Patient-centred cancer care: a road less travelled

An investigation in Australian radiotherapy settings

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THESIS
Declarations

Statement of originality
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# TABLE OF CONTENTS

Declarations................................................................................................................................. ii

Acknowledgements.................................................................................................................. iii

TABLE OF CONTENTS.............................................................................................................. VI

List of citations of publications included in thesis ................................................................. ix

List of citations of additional relevant publications not included in thesis ......................... x

List of tables, figures and supplementary materials.............................................................. xi

ABSTRACT ................................................................................................................................. XIII

EXPLANATORY OVERVIEW ..................................................................................................... XV

INTRODUCTION ....................................................................................................................... 1

I.1 The global burden of cancer.............................................................................................. 2

I.2 The burden of cancer in Australia.................................................................................... 4

I.3 Detection and treatment of cancer .................................................................................. 8

I.4 Why focus on outpatients attending radiation oncology treatment centres? ............... 14

I.5 Quality cancer care requires a holistic, patient-centred approach................................. 22

I.6 Assessing radiotherapy patients' preferences for and experiences of care............... 29

I.7 References....................................................................................................................... 35

PAPER ONE: CANCER PATIENTS’ WILLINGNESS TO ANSWER SURVEY QUESTIONS ABOUT LIFE EXPECTANCY ............................................................. 64

1.1 Abstract............................................................................................................................. 69

1.2 Introduction ..................................................................................................................... 70

1.3 Patients and methods ...................................................................................................... 71
List of citations of publications included in thesis


List of citations of additional relevant publications not included in thesis


List of tables, figures and supplementary materials

Paper 1

**Table 1.1**: Univariate and multiple logistic regression of characteristics of 469 participants completing the patient views survey

Paper 2

**Table 2.1**: Demographic and disease characteristics of respondents and proportion with a preference for self-determined disclosure ($n = 208$)

**Table 2.2**: Proportion of patients reporting experiences of life expectancy disclosure in alignment with preferences ($n = 175$)

**Figure 2.1**: Method of classification of cancer patient perceptions of life expectancy disclosure into patient self-determined or other-determined categories

Paper 3

**Table 3.1**: Multiple logistic regression analysis of demographic and disease characteristics of those with a HADS classified likely presence of anxiety

**Table 3.2**: Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of depression

**Table 3.3**: Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of psychological distress

Paper 4

**Table 4.1**: Characteristics of the sample

**Table 4.2**: Number and percentage of patients whose HADS anxiety levels agree with their perceived anxiety levels
Table 4.3: Number and percentage of patients whose HADS depression levels agree with their perceived depression levels

Table 4.4: Likelihood ratio univariate and multiple logistic regression results from four logistic regression models of the outcome “current preference to be offered professional support for anxiety and/or depression” (n = 304)

Supplementary 1: Supplementary statistical analysis

Supplementary 2: Supplementary sample size calculations

Supplementary 3: Number and proportion of respondents who did not want an offer of professional support for current levels of anxiety/depression endorsing different reasons for this (Normal distress vs Mild to severe distress) (n = 237)

Supplementary 4: Self-reported willingness to accept different types of professional support if experiencing anxiety or depression (n = 193)

Supplementary 5: Univariate and multiple logistic regression analysis of characteristics associated with preferences for professional support (n = 193)

Supplementary 6: Number and proportion (with 95% CIs) of patients indicating that if experiencing anxiety or depression, they would be willing to accept professional support, by distress assessment method (n = 193)

Paper 5

Table 5.1: Survey items and descriptions (each assessing a different domain of care)

Table 5.2: Demographic and disease characteristics of respondents (n = 344)

Table 5.3: Proportion who reported that their wellbeing would have been improved by better care across 8 domains (n = 344)

Table 5.4: Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvement

Figure 5.1: Percentage of respondents endorsing 0–8 domains in which better care would have greatly improved their wellbeing
ABSTRACT

Cancer is a common health issue worldwide, with an estimated 30 million new diagnoses in the last five years. For over half of all newly diagnosed cancer patients, radiotherapy is recommended for cancer control or symptom relief. Despite the contribution that radiotherapy makes to extended survival of those diagnosed with cancer, this treatment is associated with a broad range of potential practical, physical and psychosocial impacts. To support patients dealing with this treatment burden, a holistic patient-centred approach to cancer care is needed. This thesis by publication reports on radiotherapy outpatients’ perceived experiences of cancer care, and the degree to which these experiences were responsive to their needs, values and preferences (i.e. patient-centred). The thesis introduction provides an overview of the burden of cancer worldwide and in Australia, and includes a review of the patient-centred cancer care literature, with a focus on radiotherapy settings. The five journal papers that comprise the thesis body report on findings from a cross-sectional study of cancer patients. Cancer patients were recruited from the radiotherapy treatment waiting rooms of four Australian metropolitan treatment centres during 2010. Radiotherapy outpatients’ perceptions of care were examined across three areas that resonate with the cancer care experience:

(1) Life expectancy disclosure (Papers One and Two)

(2) Psychosocial well-being and support preferences (Papers Three and Four)

(3) Quality of patient-centred care (Paper Five).

The thesis discussion provides an overview of the strengths and limitations of this work, and implications of this thesis for future research. The study that forms the basis
of this thesis is the first large Australian study in radiotherapy settings to assess cancer outpatients' preferences and experiences for patient-centred care. Study limitations include the restriction to English-speaking-cancer patients in metropolitan radiotherapy treatment centres, and the use of a cross-sectional design. Future research should move toward developing interventions that could be appropriate for improving patient-centred cancer care for patients receiving radiotherapy.
EXPLANATORY OVERVIEW

Cancer patients may experience profound physical and psychosocial consequences related to the diagnosis and treatment of cancer and its symptoms. Individual patients’ needs and preferences for cancer care vary. Holistic, patient-centred cancer care can be defined as an approach to care that is responsive to individual cancer patients’ needs, values and preferences. The publications included in this thesis make a significant contribution to describing perceptions of patient-centred care amongst cancer patients undergoing radiotherapy treatment. The findings reported in these papers suggest that subgroups of patients may be less likely to receive patient-centred cancer care.

This thesis by publication includes an introduction, five manuscripts and a general discussion providing implications and conclusions. The manuscripts included in this thesis report findings from a cross-sectional survey of cancer patients who were recruited from the radiotherapy treatment waiting rooms of four Australian metropolitan public hospital treatment centres during 2010. All five papers have been published.

The Introduction describes the burden of cancer in both the global and Australian contexts. The processes involved in cancer detection and treatment are described, with a focus on the primary cancer treatment modalities (i.e. surgery, chemotherapy and radiotherapy) and the shift towards delivery of cancer care on an outpatient basis. An overview of the potential practical, physical and psychosocial burden of outpatient radiotherapy is used to highlight the need for a holistic, patient-centred approach to cancer care. The literature assessing outpatients’ perceptions of patient-centred cancer care is reviewed. From this it is argued that there is a need to assess radiotherapy
outpatients’ experiences of cancer care, and explore the degree to which cancer care is responsive to patients’ preferences (i.e. is patient-centred).

An important component of high-quality patient-centred care is providing information and communication whilst being responsive to patients’ needs and preferences. Research should also be responsive to variations in patients’ needs and preferences, particularly when the research addresses sensitive topics. **Paper One** describes a patient-centred approach to conducting survey research into life expectancy communication preferences and experiences. Questions about life expectancy were acceptable to a majority (70%) of radiotherapy patients, as indicated by their completion of an optional life expectancy sub-section of the survey. However, respondents who were female, older, born in Asia and diagnosed with cancer types other than breast or prostate cancer had lower odds of completing this section of the survey. This suggests that survey questions about life expectancy are less acceptable to these respondent groups. **Paper One** is published in *Supportive Care in Cancer*.

**Paper Two** presents responses of patients who were willing to answer the survey questions about life expectancy in **Paper One**. The recommended patient-centred approach to life expectancy disclosure for cancer patients was compared with radiotherapy patients’ preferences and experiences of life expectancy disclosure. Agreement between patients’ preferences and experiences was poor. To move towards the recommended patient-centred approach to life expectancy disclosure, discussions about life expectancy need to be more responsive to patients’ preferences. **Paper Two** is published in *Psycho-oncology*.

**Paper Three** examines the likely prevalence of psychological distress amongst patients receiving radiotherapy treatment. The Hospital Anxiety and Depression Scale (HADS) was used with anxiety and depression classified by subscale threshold scores
of ≥11, and a total score of ≥15 to classify overall psychological distress. The likely presence of anxiety was found to be 15%, likely depression was 5.7% and likely psychological distress was 22%. Compared with breast cancer patients, prostate cancer patients had significantly lower odds of being likely cases of anxiety and overall psychological distress, and showed a trend towards lower odds of being likely cases of depression. When grouped together, respondents with other common cancer diagnoses (e.g. brain, colorectal, head and neck, and lung cancers, melanoma and non-Hodgkin’s lymphoma) had more than 3 times the odds of being likely cases of depression, compared with breast cancer patients. Paper Three is published in Supportive Care in Cancer.

Single-item assessment of patients’ self-perceived anxiety, depression levels and desire for professional support is explored in Paper Four. Patients’ perceptions of distress levels provide a stronger model of association with a desire to be offered professional support, compared with HADS classifications. The majority of cancer patients indicated that they would accept professional support if they were experiencing anxiety or depression. This paper suggests that a patient-centred approach to psychological screening and referral in the radiotherapy setting may increase the uptake of psychosocial services. The question of how to balance patients’ perceived need for psychosocial support services against limited psychosocial resources is discussed. Paper Four is published in Annals of Oncology.

In Paper Five, radiotherapy patients’ perceptions of patient-centred cancer care are presented. Respondents to a touch screen computer survey were asked to indicate whether better care across eight domains of patient-centred care would have greatly improved their well-being. Almost one-third of radiotherapy patients identified more than one domain where better care would have greatly improved their well-being. Over
20% of respondents endorsed “Information and communication about cancer and care” and “Emotional and spiritual support” as areas where better care would have improved their well-being. Migrants to Australia (compared with Australian-born respondents) and younger cancer patients (compared with older cancer patients) had higher odds of identifying multiple domains where better care would have greatly improved their wellbeing. Paper Five is published in *BMJ Open*.

The **Discussion** summarises the key thesis findings and outlines the potential implications of these findings for future research and provision of patient-centred care. The study that forms the basis of this thesis is the first large Australian study to assess cancer outpatients’ preferences and experiences for patient-centred care in radiotherapy settings. Strengths of this study include a high consent rate and the combined use of validated and novel approaches to measuring patient outcomes and perceptions of patient-centred care. Study limitations include the restriction to English-speaking-cancer patients in metropolitan radiotherapy treatment centres, and the use of a cross-sectional design. Future research should move toward developing interventions that could be appropriate for improving patient-centred care for cancer patients receiving radiotherapy.
INTRODUCTION
I.1 The global burden of cancer

I.1.1 Cancer aetiology

Cancer refers to a complex group of diseases which are known medically as “malignant neoplasms”. These diseases are characterised by uncontrolled division of abnormal cells in a part of the body, usually resulting in a malignant tumour or growth [1]. These abnormal cells have the ability to detach from the original tumour site and spread through the bloodstream or lymphatic system [2]. These cancer cells may spread to areas of the body adjoining the original tumour site and to other bodily organs [2]. Most cancers are named after the organ in which they originate [1]. Cancers may also be distinguished by the type of cell involved. For example, carcinomas begin in the skin or tissues that cover internal organs; haematopoietic cancers start in the bone marrow or other blood-forming tissues; and sarcomas start in connective tissues such as cartilage, muscle or bone [3]. If a cancer spreads (metastasises), the new growth (secondary tumour) bears the same name as the original growth (primary tumour) [4].

There are a wide range of possible risk factors for cancer, some modifiable and others non-modifiable [4-7]. These include genetic factors, lifestyle factors (e.g. tobacco use, diet and physical activity) and environmental exposure to carcinogenic factors, including chemicals (e.g. tobacco and asbestos), radiation (e.g. ultra-violet and ionising radiation) and viruses or infections (e.g. hepatitis B and C viruses, and human papilloma virus) [4-7]. Although modifiable risk factors such as tobacco use and diet dictate the need for preventive care to improve cancer control [8], there is also a need for continued improvements in the early detection [9] and treatment of cancer [4, 10, 11].
I.1.2 Prevalence of cancer

It is estimated that in 2008, 28.8 million adults worldwide had been diagnosed with cancer over the previous five years [12]. Almost half of this burden existed in developed countries, where there is more widespread access to high-quality technical care. Worldwide, the primary tumours with the highest five-year prevalence are breast, colorectal, prostate, lung and stomach cancers [12]. This prevalence reflects increased cancer incidence and improved cancer survival, and has led to the conceptualisation of cancer as a chronic condition [13, 14].

I.1.3 Cancer incidence, mortality and survival

Cancer is a leading contributor to morbidity and mortality worldwide [10]. In 2008 there were approximately 12.7 million new cancer cases and 7.6 million cancer-related deaths globally [10, 15]. By 2030, it is expected that global cancer incidence will have risen by 75% to 22.2 million, and deaths will have increased by 72% to 13.1 million [16]. In 2008, the most commonly diagnosed cancers worldwide were lung, female breast, colorectal and stomach cancers, accounting for over 41% of all cancer cases [17]. There is an increasing trend in the incidence of breast, prostate and colon cancers worldwide [10]. This has been attributed to a combination of lifestyle changes in both developed and developing countries, and to ageing populations in much of the developed world [10]. The increasing global cancer incidence trend can also be partly explained by the development and application of technology for cancer screening and early detection [9, 18, 19].

Cancer survival is typically defined as the percentage of patients who are alive at a set period of time (e.g. five years) following their initial diagnoses [20]. This “five-year survival rate” is calculated relative to the survival of persons without cancer in the general population of the same age and sex. Five-year survival rates appear to be
increasing for cancers such as testicular cancer, bowel cancer, breast cancer, melanoma and Hodgkin’s disease [21, 22]. This is thought to reflect improvements in the early detection and treatment of cancer [14]. However, survival rates vary by cancer type and country [14, 23]. It is estimated that in 2008, about 70% of all cancer deaths globally occurred in low- and middle-income countries. Lung, stomach, liver, colorectal and female breast cancers were the most common causes of cancer death, accounting for more than half of all cancer deaths worldwide [17].

I.1.4 Disease and economic burden of cancer
In 1993, the World Health Organization Global Burden of Disease Study Group developed an indicator of global burden of disease, described as the number of years of healthy life lost due to disability or early death [24]. This indicator is termed "disability adjusted life years (DALYs)" [24]. In 2004, cancer was associated with 83 million years of healthy life lost due to death and disability [25]. This premature death and disability associated with cancer had the greatest economic impact of all causes of death and disability worldwide [25]. In 2008, the economic impact of 17 of the most common cancer diagnoses comprised 1.5% of the world’s gross domestic product, or US$895 billion [25]. This is exclusive of direct medical costs [26].

I.2 The burden of cancer in Australia
I.2.1 Prevalence of cancer in Australia
The prevalence of cancer is increasing in Australia, in that each year there is an increasing number of people who are directly affected by cancer. It is estimated that in 2007, there were 339,077 people in Australia who had been diagnosed with cancer during the previous 5 years and were still alive. This five-year prevalence represented 1.6% of the Australian population at that time [3]. Amongst males, prostate cancer had the highest five-year prevalence (accounting for 39% of prevalence), whilst amongst
females, breast cancer was the highest (accounting for 36% of prevalence) [3]. The 26-year prevalence in Australia (from 1982 to 2007) was 774,674 [3].

1.2.2 Trends in cancer incidence, mortality and survival in Australia

Cancer is a common health issue in Australia, with 114,137 new cases diagnosed during 2009 [3]. Recent figures indicate that 1 in 2 Australian men, and 1 in 3 Australian women, will be diagnosed with cancer in their lifetimes. Between 1982 and 2009, incidence rates increased from 383 per 100,000, to 486 per 100,000 [3, 27]. It is projected that the cancer incidence rate will increase in Australia, as a result of an ageing population, population growth, and increased application of screening and early detection tests [19]. Recent estimates indicate that the most commonly diagnosed cancer types (in order of decreasing incidence) amongst women are breast cancer, bowel cancer, melanoma of the skin, lung cancer and uterine cancer. For men, the most commonly diagnosed cancer types are prostate cancer, bowel cancer, melanoma of the skin, lung cancer, and non-Hodgkin lymphoma [3].

Whilst cancer incidence increased over the period 1982–2009, there was a corresponding reduction in age-standardised cancer mortality rates from 209 to 174 deaths per 100,000 people [28]. In 2011, cancer accounted for almost 30% of all registered deaths in Australia [29], making cancer the second leading cause of mortality in Australia (following cardiovascular disease). Cancer patients’ five-year survival rate has increased from 47% in the 1982–1987 period to 66% in the 2006–2010 period [30]. Diagnoses of testicular cancer, thyroid cancer, melanoma, breast and prostate cancer are associated with five-year survival rates of over 85%. Cancer diagnoses with lower survival rates include stomach, brain, lung and pancreatic cancers, at 25%, 19%, 12% and 5% respectively [3].

1.2.3 Disease burden of cancer in Australia
Cancer and cancer treatment place a significant burden of poor health, mortality and social, emotional and economic costs on patients, carers and the Australian community [3, 31, 32]. In 2012, cancer accounted for approximately 19% of the total burden of disease and injury in Australia [3]. In 2012, cancer was estimated to account for the loss of 457,400 DALYs due to early death and 93,900 DALYs due to disability [3].

1.2.4 Economic burden of cancer in Australia

Australia has a universal healthcare system, financed primarily through taxation and general government revenue [33]. All Australians are part of a government-regulated national health insurance scheme, known as “Medicare” [33]. Australian healthcare is delivered by a combination of public and private providers. Publically funded healthcare services include inpatient care and most outpatient care delivered in public hospitals. The costs of these services are “bulk billed”, meaning healthcare providers are reimbursed by the government according to Medicare Benefit Schedule (MBS) fees that correspond to particular services or “items”. Bulk billing allows patients to avoid incurring any direct healthcare costs [33]. Some healthcare may be associated with out-of-pocket costs, either because services are only partially subsidised, or because private providers charge more than the allocated MBS item fees. The Medicare Safety Net covers 80% of further healthcare costs once an annual healthcare expenditure threshold is reached, limiting the out-of-pocket medical expenses incurred by individuals. Australia also has a Pharmaceutical Benefits Scheme (PBS) with a similar safety net policy enabling affordable access to some prescription medications. Individuals who purchase additional private insurance may have enhanced access to supplemental health services (e.g. optometry, dentistry and podiatry), can choose between treatment in public and private facilities, and are offered a choice of doctor
Privately provided healthcare services typically require a combination of private health insurance rebates and patient co-payments to reduce out-of-pocket costs [34]. It is estimated that in the 2004−2005 financial year, Australia had recurrent health expenditures of $75.2 billion (i.e. medical, dental, optical services for inpatients and outpatients, prescription pharmaceuticals, community mental health services, disease screening services and research). These expenditures represented 8.4% of gross domestic product at this time. Cancer-related expenditures were $3.8 billion during this time period, representing 7% of recurrent health expenditures attributable to disease and injury groupings [35]. In the 2010−2011 financial year there were 880,432 cancer-related hospital separations (discharged patients), of which 75% were same-day separations (i.e. patients admitted and discharged from hospitals on the same day) [3, 36]. Cancer patients accounted for 2.31 million patient bed days. The average length of cancer-related hospital stays was approximately 7.6 days (excluding same-day hospitalisations) [3]. Cancer was responsible for 8.6% of all hospitalisations, suggesting a large impact of cancer on health services in Australia [3, 36].

I.2.5 Cancer as a public health priority area in Australia

In 1996, cancer control was recognised by the Australian Commonwealth, State and Territory Governments within the National Health Priority Areas (NHPA) initiative [37, 38]. The NHPA initiative provides guidance on the allocation of government health resources [39], including public health responses aimed at addressing cancer control [40]. This has included development and implementation of clinical practice guidelines for common cancers, implementation of national cancer screening programs, and prioritised research funding allocation [39, 41]. Over the past 20 years, a range of Australian federal and state government and non-government organisations have assumed responsibility for aspects of cancer control [42]. In 2006, Cancer Australia
was established by the Australian federal government as the lead cancer control agency in the country. Cancer Australia works to reduce the impact of cancer on patients, families and carers by improving patient well-being, and driving national strategies for cancer prevention, screening, diagnosis, treatment and supportive care [43].

I.3 Detection and treatment of cancer

I.3.1 Detection of cancer

The delivery of cancer care is complex as it covers a range of areas: prevention; screening, early detection and diagnosis; treatment; and survivorship or palliation. Screening tests are available for some cancer types, such as cervical, breast, colorectal and prostate cancers [44]. Screening enables early detection of these cancers (often before any symptoms are present), thus leading, in some cases, to better treatment outcomes [45-48]. For other cancers, detection usually relies on the presence of certain signs and symptoms [49]. A diagnosis can be confirmed by invasive techniques (e.g. biopsy and examination of tissue samples) or through non-invasive diagnostic imaging techniques [49]. An early-stage cancer diagnosis refers to detection of cancer whilst it is small and localised (i.e. contained within the area in which it first developed). An advanced-stage diagnosis refers to detection of a cancer when it is larger or has already metastasised. Generally, cancers diagnosed at early stages are more treatable than advanced cancers [48].

I.3.2 Common cancer treatments

Diagnosis and treatment can be challenging phases of cancer care for patients. Patients are often required to navigate and coordinate diagnostic tests and various modes of treatment, in primary care and specialist departments in public or private hospitals and clinic settings [50-52]. The major treatment modalities for cancer are
surgery, chemotherapy and radiotherapy [53, 54]. Although emerging new treatments, including hormone and targeted therapies, are utilised [55], surgery, chemotherapy and radiotherapy have been referred to as the three pillars of cancer treatment [56].

**Surgery**

Surgery is a key component of care for many cancer types across the spectrum of cancer diagnosis, staging, treatment and palliation [57]. Cancer surgery is considered to be a key treatment for extending the survival of cancer patients, particularly for localised cancers [57-59]. In the treatment of cancer, surgical resection refers to an operation or procedure that involves the physical removal of cancer cells. If the cancer is detected at an early stage (i.e. localised), surgical resection can be used to completely remove the cancer. If complete removal of a tumour is likely to harm bodily organs, surgery can be used to remove part of the tumour, leaving minimal residual disease (debulking) [57, 58]. If the cancer is more advanced, surgical resection may also be used to remove solitary nodules of metastatic cancer, with the intended outcome of improving survival or palliating symptoms [57].

Surgery is usually performed within relevant anatomical specialist departments and requires hospital admission, with same-day discharge, overnight stay or extended stays for major surgery [60]. Reports from the United States of America (USA) and the United Kingdom (UK) suggest that surgery is used in the treatment of approximately 60% of cancers [57, 59]; however, this figure varies greatly by cancer type. A recent report from the UK, for example, suggests that whilst over 80% of breast and uterine cancers are treated with surgical resection, less that 10% of patients diagnosed with liver, lung, bladder, prostate or pancreatic cancers receive surgery [59]. During the 2010–2011 financial year, there were over 305,000 hospital separations for cancer-
related surgical resections recorded in Australia [36]. Surgery may be used alone to
treat cancer, or may be combined with, or replaced by, other treatment types.

Chemotherapy
Chemotherapy describes a process of cancer treatment, control or palliation requiring
infusion of a drug (or combination of drugs) into the body, with the aim of killing cancer
cells [61]. Chemotherapy is generally used as a component of a treatment regimen that
also involves surgery or radiotherapy. Chemotherapy provided after surgery to target
residual cancer cells is referred to as adjuvant chemotherapy. If chemotherapy is used
to shrink a cancer tumour prior to surgery or radiation therapy, it is referred to as neo-
adjuvant chemotherapy [61]. Chemotherapy is typically administered intravenously, but
can also be delivered orally, topically, or directly into muscle, body cavities, arteries or
the spinal cord [62]. In addition to killing cancer cells, chemotherapy can affect almost
every organ in the body. A variety of treatment schedules are used for chemotherapy,
with drug infusion occurring in doses lasting from 30 minutes to up to several hours,
and delivered on a daily, weekly or monthly basis by chemotherapy nursing staff. To
reduce the toxicity of chemotherapy on non-cancerous cells, doses are usually given in
regular cycles, consisting of treatment days (often consecutive days) separated by rest
periods [61].

In Australia, chemotherapy is typically delivered in hospital-based or free-standing
infusion clinics. The chemotherapy team typically includes medical oncologists,
chemotherapy nurses, and pharmacists [63-65]. Depending on the admission practices
of each hospital or state, people receiving this treatment may either be counted as
inpatients (usually admitted and separated on the same day) or outpatients (non-
admitted) [36]. Optimal treatment utilisation rates are defined as the proportion of
cancer patients who, according to evidence-based guidelines, should receive a
treatment modality at least once during their cancer care [66]. These rates are used to provide a benchmark against which to assess the adequacy of treatment services [67, 68]. The optimal chemotherapy utilisation rate for cancer is thought to be approximately 51% [67, 68], but this varies from 3% for thyroid cancers to a high of 94% in myeloma [67, 68]. In Australia, the actual chemotherapy utilisation rate for all cancers is estimated to be as low as 19% [69].

Adjuvant or neo-adjuvant chemotherapy is considered useful for breast cancer, colorectal cancer, pancreatic cancer, sarcoma, testicular cancer, ovarian cancer and certain lung cancers [70]. During the 2010−2011 financial year, there were 352,396 hospital separations recorded for chemotherapy (nearly all of them same-day procedures) in public hospitals, private hospitals and other free-standing clinics in Australia [36]. Additionally, there were approximately 129,827 public hospital outpatient (or ambulatory) chemotherapy services recorded in the National Outpatient Care Database, which is based on the National Minimum Data Set for Outpatient Care [36]. This is indicative of the number of occasions of service, rather than the number of people treated with chemotherapy Australia-wide.

\textit{Radiotherapy}

Radiotherapy (or radiation therapy) is a major component of cancer treatment for many cancer patients, particularly for controlling localised tumours [71, 72]. Radiotherapy may also be given prior to surgery to shrink the tumour to make it easier to remove (neo-adjuvant radiotherapy) or after surgery to get rid of any remaining cancer cells (adjuvant radiotherapy). Treatment is delivered at designated radiotherapy treatment centres, which are usually attached to major hospitals [73]. Radiotherapy is most commonly delivered as external beam radiotherapy, which involves the delivery of ionising radiation (e.g. x-rays, electron beams and gamma rays) from large linear
accelerators. Treatment can also be delivered from within the body as internal radiotherapy (brachytherapy), which requires the surgical placement of slow-release radioactivity, either through needles directly into the tumour (e.g. for breast, prostate, and head and neck cancers) or in a body cavity near the tumour site (e.g. for cervical and vaginal cancers) [74]. Radiotherapy works by destroying rapidly dividing cancer cells in the localised treatment area. Radiotherapy treatment cures some cancers, can reduce the likelihood of a cancer coming back after surgery, and may also be used to reduce cancer symptoms [75].

The radiotherapy team includes radiation oncologists, radiotherapists, radiotherapy nurses and radiation oncology medical physicists (ROMPs) [72]. This team often works within a multidisciplinary cancer care team, including surgeons, medical and haematological oncologists, palliative care physicians, general practitioners, oncology and palliative care nurses, and other allied health staff [63, 65]. Radiotherapy treatment consists of an extended medical assessment, treatment planning or simulation, treatment delivery, on-treatment review, and follow-up care [76, 77]. The planning phase typically involves the development of individual treatment plans, the placing of “tattoo” marks on the skin to identify the treatment field, and orienting the patient to the treatment centre. Orientation generally includes the provision of information about change rooms, waiting rooms and treatment processes, including the use of immobilisation devices to restrict movement during treatment [75, 78]. Each treatment typically requires patients to lie on a table under a linear accelerator machine and converse with the radiotherapists through an intercom system. Radiotherapy treatment courses are typically delivered on an outpatient basis in daily doses (or “fractions”). Treatment usually lasts between 1 and 8 weeks, and is delivered on five consecutive days, followed by two consecutive rest days [76, 78-80]. This usually involves daily
contact with radiotherapists and weekly check-ups with a radiation oncologist or a radiation oncology registrar [77, 81].

At least one course of radiotherapy is recommended for between 48% and 52% of all cancer patients [71, 82]; of these patients, the intent of treatment would be radical (aiming for cure or extended survival) for 78-84% and palliative (aiming for symptom relief) for 16-22% [82]. Over one-fifth of those who receive radiotherapy are likely to require retreatment with radiotherapy [83]. Radiotherapy patients are also required to attend routine follow-up visits with a radiation oncologist in the years following treatment [76]. The optimal radiotherapy treatment utilisation rate varies from 0% for liver cancer through to 94% for vaginal cancer. A study in one Australian state reported that the actual radiotherapy utilisation rate for all cancers during 1999–2008 was 38% [84]. In the 2010–2011 financial year in Australia, there were MBS claims for over approximately 925,000 doses of megavoltage radiotherapy (the main form of radiotherapy used to treat cancer), 4000 claims for brachytherapy, and over 200 claims for stereotactic radiation therapy (the delivery of a concentrated dose to a precise area such as the brain) [85].

I.3.3 A shift towards outpatient cancer treatment

Cancer care is usually delivered on an inpatient basis (requiring overnight stay at the hospital/treatment centre), or on an outpatient or non-admitted basis (where patients receive care but are not required to stay overnight). As technological advancements have improved the early detection of cancer, and drugs have become available for managing cancer symptoms and treatment side-effects, there has been an increasing trend towards the delivery of cancer services in outpatient settings in Australia and other developed nations [86-88]. Of the three cancer treatments described above, surgery is primarily an inpatient service, delivered within different specialist surgery
departments. Chemotherapy can be delivered on an inpatient or outpatient basis, either at home (for some oral chemotherapy agents) or in day procedure centres [89]. Radiotherapy services are delivered primarily on an outpatient basis at specialised treatment centres [76, 90]. Compared with closely managed inpatient cancer care, outpatient cancer care requires patients to take greater responsibility for self-management of side-effects and symptoms whilst away from the support of healthcare professionals [76, 91]. This has led to a growing emphasis on ensuring that service delivery and information provision in outpatient settings are optimal [86, 87, 92, 93].

1.4 Why focus on outpatients attending radiation oncology treatment centres?

Radiotherapy is the most common outpatient cancer treatment modality in Australia. It is also the treatment that is the second most important for the control and cure of cancer [94]. As reported earlier, the overall 5-year cancer survival rate in Australia is 66% [30]. Approximately 49% to 60% of cured cancer cases can be attributed to treatment by surgical resection, 40% to radiotherapy (alone or in combination with other treatments), and 11% to chemotherapy (alone or in combination with other treatments) [54, 95, 96]. This represents attributable overall survival gains of approximately 22% for surgical resection, 16% to 18% for radiotherapy [54, 95-97], and just 2% to 6% for chemotherapy [54, 95, 98, 99]. Despite the sizeable contribution of radiotherapy to improved cancer survival, the public awareness of the role of radiotherapy in cancer treatment is low [94].

Radiotherapy treatment often involves daily treatment sessions, delivered on a Monday to Friday schedule for between 1 and 8 weeks [76, 78-80]. An average external beam radiotherapy course consists of 19 treatment attendances [100]. As most patients wait up to 20 minutes on each treatment day for their scheduled appointment [101], the
radiotherapy waiting room provides multiple opportunities to identifying problems that cancer patients may be experiencing [102]. Throughout radiotherapy, patients have routine and repeated contact with a range of nursing, radiotherapy and radiation oncology staff in the radiation oncology treatment centre. Patients usually have weekly check-ups with a radiation oncologist and daily contact with radiotherapists and nursing staff during their treatment session [77, 81]. These staff members are arguably well-placed to provide information, education and support to patients throughout their radiotherapy treatments [77, 103-105]. However, research and research priorities identified for Australian radiotherapy settings tend to focus on technical aspects of radiotherapy [106-108]. It is only recently that research in these settings has considered radiotherapy patients’ experiences of cancer care [105]. A survey of 18 radiation oncology departments in Australia suggested radiation-therapist-derived research priorities for patient care include themes such as communication, education, psychosocial support, symptom management and improved treatment techniques. However, the perceived importance of these research themes varied significantly across the departments that responded to the survey [105]. Governments, healthcare organisations and research groups in the UK, Canada, The Netherlands and Australia have recently recognised the need to examine the cancer care experiences of radiotherapy patients, in order to improve the quality of cancer care [79, 109-113].

I.4.1 Developments in radiotherapy service delivery in Australia

Over the past 20 years, radiotherapy service delivery has increasingly become part of the national political agenda in Australia. In 2002, the Baume radiation oncology inquiry report, A Vision for Radiotherapy, acted as a catalyst for radiation oncology quality and safety improvement, through proposed reform of radiotherapy infrastructure and workforce [114]. The overarching aim was to work towards meeting the benchmark
optimal radiotherapy utilisation rate for cancer patients. This report highlighted the impacts of fragmentation between state and federal levels of government on radiotherapy service delivery, and recommended that a national body (later known as the Radiation Oncology Reform Implementation Committee) be established for radiotherapy planning, quality and funding purposes [114]. The Tripartite Committee, made up of organisations representing the three key professions involved in radiation oncology (i.e. radiation oncologists from The Royal Australian and New Zealand College of Radiologists, radiotherapists from the Australian Institute of Radiography, and ROMPs from the Australasian College of Physical Scientists and Engineers in Medicine), was funded to draft best practice standards for radiation oncology [72]. The report, *Planning for the Best: Tripartite National Strategic Plan for Radiation Oncology 2012−2022*, was prepared by the Tripartite Committee [72].

### I.4.2 State-based radiotherapy service planning in Australia

Despite having an Australian national vision for radiotherapy service delivery, service planning is still largely state-based [72, 115]. This thesis will focus on radiation oncology settings in the Australian state of New South Wales (NSW), which has the highest population of all states and territories in the country, with an estimated 6,984,172 residents in 2008. Australian MBS item reports on claims for computerised planning for radiotherapy can be used as a proxy indicator of the number of new and retreatment radiotherapy courses delivered. Of 96,212 planning sessions Australia-wide in the 2010−2011 financial year, almost one-third (30,408) were in NSW. The Statewide Services Branch of NSW Health has overarching responsibility for services such as radiotherapy [115]. This group has recently released the *Radiotherapy Services in NSW – Strategic Plan to 2016*, which focuses on infrastructure and workforce issues in radiotherapy [116]. This strategic plan primarily focuses on
responsiveness to an increasing demand for radiotherapy services, and improving access through broader geographic distribution of treatment facilities and increased workforce capacity.

I.4.3 Geographic and financial barriers to accessing radiotherapy in New South Wales

Although outpatient-delivered radiotherapy treatment is thought to be less disruptive to patients’ lives than inpatient hospital-delivered treatments [117], there are issues surrounding access to treatment and waiting times. This includes both the time from referral to first radiotherapy treatment, and treatment centre waiting times for daily appointments. Access to radiotherapy in NSW can also be limited by geographical factors, with the average distance from patients’ homes to radiotherapy treatment centres estimated at 40 kilometres, compared with the average distance to chemotherapy infusion services of 12 kilometres [118]. As of June 2010, in NSW there were 14 public radiation oncology treatment centres, and five private centres [116]. The number of linear accelerators in public facilities is planned to increase from 37 in 2010 to 46 by 2016. Private facility linear accelerators are likely to increase from 9 to approximately 15 by 2016 [116].

For patients who have to travel long distances for treatment or arrange accommodation away from home for the duration of their treatment, there can also be financial impacts of treatment [119-122]. Qualitative research in Australia has identified that some patients may be unable to continue work or maintain their usual roles or routines during treatment, particularly if they need to relocate for radiotherapy [120]. A review identified that travel for treatment appeared to be a barrier or inconvenience faced by some cancer patients [123]. From 2012, the Australian Federal Government Isolated Patients Travel and Accommodation Assistance Scheme has provided accommodation and travel subsidies for patients who need to travel in order to access outpatient
radiotherapy [80]. However, there are still likely to be out-of-pocket expenses for some patients.

1.4.4 Physical side-effects of radiotherapy

The short-term side-effects of radiotherapy vary greatly, depending on the area of the body being treated, the dosage level, the number of treatments, and other factors [76, 78]. Radiation damages bodily tissues at the cellular level, and areas surrounding the tumour site may be subject to acute and late effects. Radiotherapy commonly leads to reactions of the skin (e.g. dryness, irritation and hair loss) due to radiation beams passing through the skin to the target site. Radiotherapy may also lead to inflammation of the oral and gastrointestinal mucous membranes, which are radiosensitive, protective tissues present in body passages and cavities that are directly and indirectly connected to the external environment (e.g. oral cavities and anus) [76]. This inflammation may result in mucositis and ulcerations, which may be associated with uncomfortable and distressing treatment toxicities, including nausea, diarrhoea and pain, that may impact on a patients’ ability to maintain an adequate nutritional intake [124]. Other common side-effects experienced during radiotherapy include sleeplessness, fatigue, loss of appetite and taste, bladder and bowel irritation, cough and shortness of breath (dyspnoea), and difficulty swallowing (dysphagia) [76, 124, 125]. These effects are likely to worsen throughout the course of treatment due to cumulative effects of irradiation.

Radiotherapy may also interact with other treatments, such as chemotherapy, adding to treatment toxicity. Some side-effects may arise after treatment is completed [126], and patients who have not been given adequate information may not associate these effects with earlier treatment [124]. Reactions to treatment that arise more than 90 days after radiotherapy commencement are referred to as late effects [127]. For example,
patients who received irradiation to the chest or thorax (e.g. those being treated for breast cancer, lung cancer, oesophageal cancer and lymphoma) may develop radiation-induced heart disease years after radiotherapy [128, 129]. Second malignancies also become more likely as the length of time since treatment increases [129, 130]. Radiotherapy patients need to absorb much information about what physical symptoms and side-effects to expect in the short-, medium- and long-term, and how to manage these. Given that radiotherapy is primarily delivered on an outpatient basis, there is a heightened need for communication and planning during treatment visits, so that patients have the ability to self-manage side-effects, and know when to request additional support for this.

I.4.5 Psychosocial impact of cancer and radiotherapy

*Uncertainty during radiotherapy – patient information and communication needs*

Radiotherapy may be stressful for patients, particularly at the beginning of treatment when they are faced with uncertainty about the treatment environment, processes, side-effects and treatment outcomes [76, 81, 112, 131]. In Australia, Halkett and colleagues [112] interviewed 34 patients diagnosed with early-stage breast cancer who were undergoing radiotherapy. Interviews were conducted at four time points during the treatment pathway: meeting the radiation oncologist; treatment planning; first day of treatment; and approaching the end of treatment. It was identified that in the lead-up to treatment, patients need to process complex medical information and make important treatment decisions with their radiation oncologists [112]. Patients also reported feeling underprepared for radiotherapy treatment planning and the experience of commencing treatment. There were also concerns about not knowing what to expect after treatment completion, including what side-effects to look out for [112].
Radiotherapy may be provided as a curative or palliative treatment. For some patients, the outcomes they expect from radiotherapy may be in conflict with the actual aim of treatment (i.e. curative or palliative) [132]. Discussions about radiotherapy treatment aim, likely prognosis and life expectancy may assist patients to make informed treatment decisions [133]. However, cancer patients often report concerns and unmet needs related to life expectancy information and communication [134-136]. Qualitative research in the UK interviewed 15 cancer patients six months following their radiotherapy treatment, and identified that patients indicated a need for additional communication of information about their treatment and prognosis [137]. The importance of staff having a respectful interpersonal demeanour was also emphasised by patients [137]. There is a need to explore radiotherapy patients’ experiences of life expectancy discussions during their cancer care, and whether these discussions have been respectful of and responsive to patients’ preferences [133, 138].

**Burden of psychological distress during radiotherapy**

Elevated levels of psychological distress, including anxiety and depression, have been reported in cancer patients undergoing radiotherapy [139-142]. During treatment, patients often take on the responsibility of managing their side-effects and coordinating their cancer care. The presence and intensity of some cancer symptoms and radiotherapy side-effects have been associated with elevated psychological distress [143-149]. Although there is a large body of research on prevalence and risk factors of psychological distress in cancer patients in general [150-153], only a small number of studies have focused on radiation therapy patients currently undergoing treatment [139-141]. Anxiety and depression are two mood disorders that have been associated with radiotherapy, and which may impact on quality of life, adjustment to treatment, coping and self-care [139, 141]. A review by Steigelis identified 11 studies that
assessed psychological distress during radiotherapy [140]. The generalisability of many of the studies identified in this review is limited, however, due to relatively small sample sizes [139, 141, 154] and a focus on a limited range of cancer types [155, 156]. Additionally, the instruments used for assessing anxiety and depression (i.e. standardised measures and structured diagnostic interviews) in radiotherapy settings have varied, making it difficult to compare findings across studies [140, 157]. A recent study at the Medical University of Vienna, Austria, has reported the prevalence of physical, social and psychological problems and needs in a larger heterogeneous sample of radiotherapy patients [158]. There have been no Australian studies of anxiety, depression and psychological distress in a large, heterogeneous sample of radiation oncology outpatients who are currently undergoing radiotherapy [140]. Additionally, no studies have assessed patients’ perceptions of the level of anxiety and depression they are experiencing during radiotherapy and their preferences for professional psychosocial support [159-161].

**Impacts of radiotherapy on social roles and relationships**

The impact that radiotherapy can have on usual social roles, relationships and employment may also mediate patient well-being [76]. Brennan [162] proposed that if treatment reduces the opportunity to engage in usual social and work roles and routines, there may be negative impacts on patients’ sense of control, competence and self-worth. This may lead to poorer adjustment to cancer and cancer treatment [162]. A large qualitative study of breast cancer patients in Sweden described some of the strategies that women use to cope with radiotherapy [163]. The themes emerging from this work suggested that continuing usual life activities and maintaining family, friendship and workplace support networks is important for a sense of normalcy throughout treatment [163]. Muniz and Zago used an anthropological interpretive
approach to determine radiotherapy patients’ experiences, and identified one theme, i.e. the impact of changes in body appearance, including the use of skin markings (“tattoos”) to guide treatment, with potential impacts on patient body image [164]. There may also be impacts on sexual functioning following irradiation of some sites (e.g. for gynaecological and genitourinary cancers) [165, 166]. A study of Swedish cervical cancer patients who were 5-years’ post-treatment reported that radiotherapy was associated with reductions in libido, vaginal length and elasticity. These side-effects may lead to discomfort and distress related to sexual intercourse [166]. It has been identified that almost two-thirds of Australian cancer patients report not receiving enough information about how cancer treatment may be associated with changes to their relationships and sexual activity [167].

The potential psychosocial impacts of cancer and outpatient radiotherapy described above emphasise the need for an approach to cancer care that enables cancer patients to understand important information about treatment and prognosis, to cope with the emotional impacts and uncertainties associated with cancer and cancer treatment, and to receive care that is responsive to their individual needs and preferences [168].

1.5 Quality cancer care requires a holistic, patient-centred approach

The USA Institute of Medicine’s widely adopted definition of quality healthcare is: “The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” [169]. Given the many physical and psychosocial challenges that cancer patients may face during outpatient radiotherapy (e.g. practical and access issues, physical side-effects, emotional distress, changes to usual social roles, and the need to understand important and complex information about treatment procedures and likely prognosis), it
is recognised that a holistic and patient-centred approach to care is needed to optimise patients' experiences of care and desired health outcomes [76, 81, 109, 170].

Patient-centred care describes healthcare interactions and experiences that inform and support patients and their families (when appropriate), to be involved in their care in a manner that is responsive to and respectful of individual patients' values, preferences and desires [171-175]. Stewart and colleagues have described patient-centred care as an interactional style characterised by the sharing of power and agenda setting in communications between health professionals and patients, enabling movement towards an understanding of the patient as well as the disease [176]. Patient-centred care has also been defined by the multiple concepts, domains or dimensions that it encompasses [171, 173, 176-181]. Mead and Bower reviewed the patient-centred care literature and identified five dimensions that conceptualised how patient-centred interactions differ from what would be seen in a traditional paternalistic biomedical approach to healthcare [180]. The first was having a biopsychosocial explanatory perspective on illness and health (considering social and psychological factors alongside biomedical factors). The second was shared power and responsibility between patients and clinicians. The third was a therapeutic alliance that attends to the social and emotional aspects of consultations to optimise therapeutic potential. The fourth dimension was understanding the patient as a person, including their illness perceptions, and the fifth was doctors' self-awareness of how their own personal qualities may influence interactions [180].

Provision of patient-centred care may contribute to improvements in patients' physical, mental and social well-being [182-184]. Descriptive studies have indicated an association between patient-centred communication (assessed in various ways) and proximal outcomes, including patients' feeling known, respected, involved, engaged
and knowledgeable [168]. Whilst these proximal outcomes are arguably desirable endpoints on their own, they may also have moderating effects on patient well-being [185]. Provision of patient-centred care for people with cancer and other chronic conditions has been associated with intermediate outcomes, such as improved treatment adherence and self-management [168, 177, 186, 187]. Patient-centred care processes have also been associated with more distal health outcomes [168], such as patient satisfaction and quality of life [177, 184]. It has been suggested that these links between patient-centred care and improved treatment adherence can be explained by self-determination theory [188, 189]. The motivation for initiating and maintaining behaviours conducive to health and well-being (e.g. treatment adherence) is thought to stem from the development of a sense of autonomy, self-perceived competence and self-perceived relatedness to others involved in care, all of which resonate with the previously outlined conceptualisations of patient-centred care.

A recent Cochrane review of interventions to promote a patient-centred approach in clinical consultations defined patient-centredness as an approach to care encouraging (a) shared control of the consultation and decisions about health management interventions between the doctor and patient, and/or (b) a consultation focus on the patient as a whole person, including their individual preferences in a social context (in contrast to a focus limited to a body part or illness). In this Cochrane review, shared treatment decision-making was considered to be a sufficient indicator of patient-centred care [190]. This Cochrane review reported mixed findings about the impact of patient-centred care on patient healthcare behaviours, patient satisfaction and health status. It concluded that a patient-centred approach is linked with low- to medium-range impacts on these outcomes. This effect seemed to be enhanced if patient-centred care was supplemented by the provision of educational materials specific to the patient’s disease.
or condition. The methodological quality of studies in this review was poor, and patient-centred care was not widely assessed in cancer patient populations, or from the patient’s perspective [190]. A study by Moira Stewart and colleagues identified that patients’ perceptions of patient-centred care was associated with improvements in health status (including less discomfort and concern, and better mental health) and increased care efficiency (e.g. fewer referrals and diagnostic tests) [191]. This effect was not found when using an expert-derived system for classification of patient-centred care. Given that judgements about whether care is patient-centred should assess the degree to which patients’ preferences for care have been elicited and met, it follows that patient-centred care is best judged from the perspective of patients, based on their experiences of care.

I.5.1 What do we know about radiotherapy outpatients’ experiences of care?

International studies of oncology outpatients’ experiences of care

Internationally, radiotherapy patients’ experiences of care have been assessed within broader population-based surveys of cancer outpatients’ experiences. Recent studies of cancer outpatients’ experiences of care have been carried out in Australia, New Zealand, the UK, North America and Europe [192-200]. The Picker Institute has worked with various agencies in these countries to develop surveys that assess the experiences of cancer inpatients and outpatients. These surveys are based on the seminal work of Gerteis and colleagues [201] who identified dimensions of patient-centred care that were valued by patients. In outpatient oncology settings, the dimensions of patient-centred care typically assessed include the following: whether care is respectful to patients’ values and needs; whether it is coordinated and integrated; whether it is accessible; whether it provides information, education and emotional support to patients; whether it addresses patients’ physical comfort; and
whether it invites involvement of family and friends [194, 202]. Comparisons of surveys from the UK, Canada, and New Zealand suggest that oncology outpatients perceive that their care was respectful and coordinated, but that the level of physical symptom management, information, communication and emotional support could have been improved [192, 193, 203-205]. Following the UK National Health Service (NHS) 2011–2012 cancer patient experience survey, the NHS National Clinical Director for Cancer has commissioned a survey specific to radiation oncology outpatients’ experiences [206].

A limitation of the population-based studies described above is that they have not recruited patients during treatment, instead focusing on care received in the previous six months [204, 205]. Over the past decade, studies assessing the preferences and experiences of radiotherapy patients, immediately before, during and after their treatment, have been published in the international academic literature. In 2004, 135 Finnish cancer patients receiving curative radiotherapy completed a questionnaire about the quality of radiotherapy nursing care that they had experienced across four categories: staff characteristics; caring activities; the caring environment; and the caring process [207]. Poorer patient ratings of quality of care were given to staff attention to patient well-being, and involving patients and relatives in planning care, discussion and explanation of treatment, prognosis and results.

Nijman and colleagues [208] conducted four focus groups and two concept-mapping meetings with cancer patients in The Netherlands who had completed radiotherapy in the previous 6–10 weeks. Seven main themes arose as important for the quality of radiotherapy: provision of appropriate and understandable information; a patient-centred approach; professional competence of staff; treatment scheduling and waiting times, and involvement of support people in the process; practical issues related to
accessibility of treatment facilities; cooperation and communication amongst healthcare providers; and follow-up care (including progress during treatment).

A recently published study reporting on research at the Medical University of Vienna, Austria, has reported that approximately one-third of a heterogeneous sample of 1500 radiotherapy patients identified physical, social and psychological problems and needs on their first visit to a radiotherapy treatment centre [158]. Over one-fifth of patients reported psychological distress, almost one-third identified support needs related to management of clinically relevant levels of pain, over one-third reported needs for assistance with everyday life activities (e.g. housework, outdoor tasks, cooking, personal mobility and care), and approximately two-fifths expressed a need for further information (including about nutrition, complementary medicine and psychological support) [158].

*Australian studies of oncology outpatients’ experiences of care*

Most Australian states have administered population-based assessments of the quality of cancer care from the patients’ perspective. Whilst these assessments have included radiotherapy patients, they have not been the focus of the assessment [198]. For example, in 2007 and 2008 an outpatient experiences survey based on the Picker Institute surveys was administered by the NSW Cancer Institute in partnership with NSW Health [209]. Respondents were identified from manually compiled patient lists, reflecting those who had received cancer care services at 16 participating sites during February of the survey administration year. Selected patients were mailed invitations to participate in the survey. A sample of 3780 outpatients (response rate 53.4%) returned the survey. Patients reported high levels of satisfaction in relation to being treated respectfully and the overall attitudes of staff; however, lower satisfaction was reported in areas of care pertaining to provision of emotional support and information [167].
Overall, 30% to 50% of cancer outpatients were dissatisfied with the level of information, emotional support, involvement of family, and some aspects of access to care. There were, however, a number of limitations to this study. Although 33% of respondents had received radiotherapy, information on treatment stage of respondents was unclear [198]. Overall, 25% were diagnosed 2–5 years prior to survey completion and 40% within the 12 months prior to survey completion [167]. This may have impacted on recall of care provided during treatment, in addition to a low consent rate impacting on the representativeness of the sample. The assessment of satisfaction was another limitation of this study. Satisfaction measurement has been criticised for not considering individual differences in patients’ expectations for care, which are likely to influence patients’ judgements of the actual care provided [210]. For example, if a patient indicates they are satisfied with a healthcare interaction, this may reflect a view that an attempt was made to help, rather than a view that the interaction was of optimal quality.

In 2009, the Cancer Council NSW conducted a call-in to the Cancer Council Helpline for radiotherapy patients and carers to share their experiences and perspectives on the practical, emotional and financial challenges of radiotherapy, through a semi-structured interview over the telephone or via e-mailed submissions. Limitations of this study include the recruitment of a self-selected sample, and the small proportion (13%) of cancer patient respondents who were currently receiving radiotherapy [211]. This study found that timely information provision, efficient appointment scheduling, and staff competency, professionalism and compassion were associated with positive experiences of radiotherapy. Negative experiences of radiotherapy resulted when physical comfort, respect, information and support were lacking in treatment centres and patient accommodation [211]. The only other research in Australian radiation
oncology treatment centres has focused on single cancer types (e.g. breast cancer) or on specific patient needs (e.g. information) [112, 212, 213]. Therefore, there remains a need for assessing the experiences of cancer care in a large heterogeneous sample of radiation oncology outpatients receiving treatment in Australia.

I.6 Assessing radiotherapy patients’ preferences for and experiences of care

The way in which individual patients experience their health, illness and treatment, and the processes of care is recognised as an important indicator of patient-centred care [214]. Assessment of patient-centred care requires patients to report on whether or not specific aspects of care were delivered, and whether this aligned with their expectations and desires [202, 204, 207]. Although patient experience surveys assess whether or not aspects of care were delivered during specific healthcare consultations, these do not always capture how well communication and care aligned with patients’ preferences and desires throughout cancer care [215, 216]. There is a need to assess radiotherapy outpatients’ preferences for and experiences of cancer care across domains of patient-centred care that resonate with the outpatient cancer treatment experience. This can be done by assessing patients’ views about specific aspects of cancer care (e.g. disclosure of information about life expectancy, and psychosocial well-being and support) or more broadly about the quality of patient-centred cancer care [168].

I.6.1 A patient survey in radiotherapy treatment centres

To collect representative views about radiotherapy patients’ preferences and experiences of cancer care, there is a need to involve patients diagnosed with a range of cancer types and at various disease stages. Although population-based cancer registries have the potential to provide access to representative samples of cancer
patients, delays in registry case ascertainment of up to 6 months mean that it is often unfeasible to recruit patients during the active treatment phase. This may create recall biases when asking patients to reflect on their experiences of care during treatment. Additionally, at the time of recruitment it is not possible to identify which patients have had radiotherapy. Collecting information from cancer patients who are attending routine radiotherapy treatment appointments has been demonstrated to be a feasible approach for capturing the views of a broad range of cancer patients [105, 217]. Using this strategy, the views of cancer patients with different cancer types, disease stages and treatment goals can be assessed during the treatment phase of their disease. Active, face-to-face clinic-based recruitment strategies are also likely to be associated with better consent rates than mailed surveys [218-220].

**Thesis overview**

This thesis reports on findings of a survey of radiation oncology outpatients from four radiotherapy treatment centres in the Australian state of NSW. Eligible patients (i.e. cancer patients aged at least 18 years old with adequate English language to complete the survey) waiting for radiation therapy treatment were invited to participate in the study by a research assistant attending the radiation oncology department. A total of 785 patients were screened for eligibility, and 659 patients were invited to participate in the study.

**A touch screen computer survey**

The patient survey was programmed into a Dell Latitude XT2 touch screen computer using Digivey software (CREOSO Corporation, Arizona). Touch screen computer surveys such as this have the potential to be implemented across a number of cancer clinic settings. Touch screen computer surveys also allow data from individual survey administration computers to be downloaded and then merged into a centralised
database, eliminating the need for data entry. Electronic data collection has been associated with less underreporting, fewer inconsistencies [221] and fewer missing values [222] than paper-and-pencil surveys. There is evidence indicating that touch screen computer surveys are viewed as a confidential, acceptable, feasible and cost-effective mechanism for collecting information about the psychosocial well-being of cancer patients [222, 223]. Consent rates for completing touch screen self-report assessments in an oncology setting have been found to reach 99.3% [224]. The touch screen computer survey in this study utilised question branching based on participant responses. This helped to ensure questions were relevant to participants and to reduce the burden of survey completion where possible.

Ethics approvals
Appropriate human research ethics approvals were obtained from the University of Newcastle Human Research Ethics Committee and the New South Wales Population and Health Services Research Ethics Committees. Research governance authorization was also sought and obtained from the participating hospitals.

Study procedure
Eligible participants were cancer patients who were attending at least their second radiotherapy appointment, aged 18 years or older, able to complete the touch screen computer survey in English, and physically and mentally able to give informed consent. A research assistant present in the radiation therapy treatment waiting room assessed patient eligibility. If research assistants were unsure whether patients were eligible to be enrolled in the study, they could seek guidance from clinic staff (e.g. about patients English level, ability to give informed consent) before initiating the informed consent process. The informed consent process involved a research assistant approaching patients in the waiting room to introduce the study and provide additional printed and
verbal information about participation. Five research assistants were involved in patient recruitment. To facilitate consistent survey administration across sites, research assistants attended an information session about: survey content, touchscreen computer survey administration, obtaining informed consent from patients, and suggested responses to participant questions. Research assistants were provided with a study recruitment manual (see Appendix 9.1). They were also required to keep a study log sheet when attending the clinic (see Appendix 9.1.1), to record consent rates and additional information that may have been relevant to the study outcomes (e.g. if patients struggled to answer questions, if the patient required assistance with administration of the touchscreen survey). Research assistants were directly supervised in the clinic by the PhD candidate coordinating the study for at least their first week of face-to-face recruitment, and then provided with remote supervision in telephone or face-to-face meetings.

Patients who agreed to participate in the study were allocated a unique identification code to log in to a touch screen computer survey, which they then completed whilst waiting for their radiation therapy treatment appointment. Survey completion was taken to imply informed consent. If patients were unable to complete the survey prior to their daily treatment, they were offered the opportunity to log back in and continue the survey once their treatment was completed.

The survey was divided into modules. Some of these were core modules which were completed by all respondents. Other modules were inserted into and removed from the survey at different times during the study period. These non-core modules were completed by consecutive subsamples of respondents. Combined with the branching capacity of the touch screen computer survey, alternation of survey modules helped to
reduce survey length so that it was feasible for patients to complete the survey whilst waiting for radiotherapy appointments.

Thesis aims

This thesis explores cancer outpatients' perceptions of care, focusing on three broad areas that resonate with the cancer care experience: discussions about life expectancy; psychosocial well-being and support preferences; and quality of patient-centred care [168]. With a focus on radiotherapy outpatients, the aims of the project which forms the basis of this thesis were as follows:

**Aim 1:** To describe the proportion and characteristics of patients who are willing to answer survey questions about life expectancy.

**Aim 2:** To examine patients' preferences for life expectancy disclosure, and explore agreement between patients’ preferences for and perceived experiences of life expectancy disclosure.

**Aim 3:** To examine the likely presence of and factors associated with anxiety, depression and overall psychological distress amongst patients.

**Aim 4:** To assess agreement between anxiety and depression levels as classified by standardised measures and by patients’ perceptions, to explore whether a standardised anxiety and depression measure or patients' perceptions of anxiety and depression provided a better measure for identifying patients who would like to be offered professional help for anxiety and/or depression, and to describe the proportion of patients indicating that they would accept professional support for anxiety or depression.
Aim 5: To describe the proportion and characteristics of patients who perceive that their well-being would have been greatly improved by better cancer care in i) specific and ii) multiple domains of patient-centred care.

Thesis structure

This thesis by publication is made up of five related papers, rather than a series of chapters. All papers are published. These papers are based on one survey that was administered to patients at four Australian radiotherapy centres. This survey contained multiple sections. In order to answer the 5 aims of this thesis (presented in Papers One to Five), some survey sections were administered to the entire participant sample (data presented in Papers One and Three), whilst other sections were administered to smaller subsamples during the study period (data presented in Papers Two, Four and Five). Detail on the electronic survey questions and skip patterns is included in Appendix 9.1.3 and 9.2. Careful consideration was given to integrating findings from this dataset into a large paper describing a broad view of radiotherapy patients’ perceptions of cancer care. However, each topic was thought to be of stand-alone importance [225, 226], with findings that could not be adequately communicated in a single published paper. Therefore, it was deemed appropriate to present the study findings as smaller, digestible messages to aid scientific communication of the findings relating to each thesis aim [227]. Each of the individual manuscripts presented in this thesis from the larger study reflects a new and significant academic contribution to the understanding of radiotherapy patients’ perceptions of patient-centred cancer care.
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PAPER ONE

Cancer patients’ willingness to answer survey questions about life expectancy

In Western countries, a consistent finding is that communication and information needs related to cancer diagnosis, treatment and prognosis are amongst the most prevalent unmet needs or concerns reported by cancer patients [1-5]. Although 53% to 81% of cancer patients want as much information as possible about their disease and prognosis [6, 7], a proportion of cancer patients indicate that they do not want information about their life expectancy, or are ambivalent [6, 8-12]. In Australia, consensus guidelines recommend a patient-centred approach to life expectancy disclosure, requiring cancer clinicians to be responsive to patients’ preferences for disclosure of this information.

There is limited research reporting on the extent to which cancer patients’ experiences of life expectancy disclosure align with their preferences [13]. Given the sensitive nature of this topic, and that a sizable minority of patients may not want to discuss their prognosis, it is crucial that potential research participants are aware of the nature of the questions that they may be asked [14]. Therefore, patients participating in a cross-sectional survey assessing a range of topics related to patients’ experiences of cancer care were provided with an opportunity to opt-out of the section of the survey containing the life expectancy questions. The advantage of this approach is that it not only allows a patient-centred approach to life expectancy research, but also enables examination of the characteristics of those who prefer not to complete questions on life expectancy. Paper One reports on cancer patients’ willingness to answer survey
questions about life expectancy when these questions are embedded within a cross-sectional survey covering a range of topics.

This paper was published in *Supportive Care in Cancer* (see Appendix 1.1).

References


Cancer patients’ willingness to answer survey questions about life expectancy

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1.1 Abstract

Purpose

This study aimed to determine the proportion and characteristics of radiation oncology outpatients who were willing to answer questions about their life expectancy.

Methods

A cross-sectional patient self-report survey was conducted using touch screen computers in Australian radiation oncology treatment centers. The primary outcome was the respondent’s willingness to complete a survey subsection about life expectancy. Demographic and disease characteristics were also collected, and level of anxiety and depression was assessed using the Hospital Anxiety and Depression Scale (HADS).

Results

Of the 469 oncology outpatients who completed the survey, 327 (70%, 95% CI: 65%, 74%) indicated that they were willing to answer questions about life expectancy. Being female ($p < 0.001$), older ($p < 0.05$), born in Asia ($p < 0.05$) and being diagnosed with cancer types other than breast and prostate cancer ($p < 0.01$) were associated with lower odds of answering life expectancy questions.

Conclusions

The opportunity to opt-out of survey questions about sensitive issues such as life expectancy is a feasible method for accessing important information about patient preferences while minimizing burden. Further research may be needed to improve acceptability of life expectancy research to some patient groups.
1.2 Introduction

A cancer diagnosis is often associated with a reduced life expectancy [1]. Therefore oncologists are often faced with the intimidating task of communicating this bad news to patients and their families [2]. Although communication training is provided in medical schools, clinicians have reported feeling inadequately trained in breaking bad news [3]. Variation in individual patient preferences for life expectancy disclosure compounds the complexity of this task for clinicians [3, 4]. Additionally, there is limited evidence about patient disease and demographic characteristics associated with different preferences [5]. Although guidelines based on consensus views have been developed to assist clinicians with the task of life expectancy disclosure [6, 7], it remains critical to build empirical evidence about how different methods of disclosure impact on patient psychosocial outcomes.

Although there is a need to build the evidence base regarding prognostic communication [5], ethical concerns about the potential burden of this research have been raised [8]. The development of a patient-centered methodological approach to assessing patients’ preferences for life expectancy disclosure may prove successful for increasing representative research output, while also minimizing the burden of research to patients in accordance with their preferences for involvement. This approach involves embedding a set of optional life expectancy questions within a larger patient experience survey and giving patients the chance to “opt-out” of these questions. It was thought that this may help to minimize patient burden, while also maximizing overall consent rates and representativeness [9]. Importantly, this approach would also allow identification of patient characteristics relating to a willingness to answer these questions, helping to improve our understanding of acceptability of the topic of life expectancy to different cancer patient groups [5].
**Aims and hypotheses**

This research aimed to determine 1) the proportion of cancer patients willing to answer survey questions about their life expectancy, and 2) examine disease and demographic factors associated with a willingness to answer these questions. We expected that females would be more likely than males to answer life expectancy questions, based on past findings suggesting females want more detailed information about cancer [10]. Based on previous research into cancer patients’ preferences for prognosis communication, it was expected that patients perceiving a shorter survival time would be less likely to complete life expectancy questions than those perceiving a longer survival time [11]. Similarly, we expected that patients reporting that their treatment had curative intent would be more willing to complete the life expectancy questions than those perceiving that their treatment was with palliative intent. It has also been suggested that willingness to participate in research trials may be linked to psychological distress; however, findings are mixed [2, 5, 12]. We expected that respondents born in some Asian and European regions may be less likely to complete life expectancy questions [4, 5], and that younger respondents would be more willing to answer the life expectancy questions [5, 11].

**1.3 Patients and methods**

**Ethical standards**

All human research was approved by the University of Newcastle HREC and the New South Wales Population and Health Services Research Ethics Committee. Research governance authorization was also sought and obtained from the participating hospitals.
Patients

Cancer outpatients were recruited from four metropolitan radiation therapy treatment centers between February 2010 and December 2010. The four treatment centers were attached to large public teaching hospitals located in high socio-economic status areas of Sydney, Australia. Patients were eligible for inclusion if they were aged 18 years or older, had a cancer diagnosis, were attending radiation therapy treatment as an outpatient, and understood sufficient English to complete the survey. Patients who were attending the clinic for the first time were excluded.

Procedure

A research assistant (RA) approached patients waiting for their radiation therapy treatment appointment. Participants were provided with a written information statement about the study. The RA explained that the survey contained questions about quality of care, coping with cancer, and an optional section about life expectancy. The RA then sought informed consent from eligible patients after indicating that the patient could choose not to complete the section on life expectancy. Once informed consent was obtained, patients completed the survey in the waiting room using a portable touch screen computer. Digivey software (CREOSO Corporation, Phoenix, Arizona) was used to program the survey, which was administered using a Dell Latitude XT2 touch screen computer. The use of touch screen computer surveys in oncology settings has been previously found to be acceptable to cancer patients [13].

Measures

The following modules were embedded within a larger 10–15-minute survey:
**Outcome measure**

The primary outcome was patients’ willingness to complete life expectancy questions. The introduction to this section of the survey read “The following questions ask for your views about your life expectancy. This will provide information that may help to improve services for cancer patients.” Participants were asked to indicate whether or not they were willing to complete questions about their life expectancy by either selecting “I am willing to complete this section of the survey” or “Please skip to the next section of the survey”. If participants initially chose to complete the life expectancy section, but then changed their mind, they could use the “BACK” navigation button on the survey screen to return to the introductory screen for the life expectancy section. This then allowed participants to skip the life expectancy section and any previous responses were deleted.

**Explanatory measures**

Demographic and disease data on age, gender, diagnosis, country of birth, time since diagnosis, number of outpatient appointments, number of oncology appointments, and treatment aim were collected via the self-report survey. The Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depression. The HADS contains two seven-item subscales each producing a score between 0 and 21 indicating normal (0-7), mild (8-10), moderate (11-14), or severe (15-21) levels of anxiety, and/or depression [14]. There is evidence that this measure is both reliable and valid in a cancer patient population [15], and produces comparable results when it is administered via paper and pencil or via touch screen computers [16]. Although various thresholds have been used in the literature to identify caseness [17], a subscale score of 11 or more can be indicative of clinically significant levels of anxiety.
and/or depression [14]. This threshold was used to classify respondents having clinically significant depression or anxiety.

Statistical analysis

The proportion of participants willing to answer survey questions about their life expectancy was estimated with a 95% confidence interval. Disease and demographic factors hypothesized as being associated with a willingness to answer these questions were examined using univariate and multiple logistic regression analyses. Because of small numbers of rarer cancer types, the cancer type variable was collapsed across low incidence categories to give the following “breast,” “prostate”, and “other” for univariate analysis. Variables of interest included age category, sex, region of birth, clinically significant anxiety, clinically significant depression, cancer type, and perceived palliative treatment aim. Variables with a $p$ value of 0.2 or less for univariate analysis were included in a multiple logistic regression model, and the backward stepwise method was used to remove variables with a $p$ value of 0.1 or greater on the likelihood ratio test. Odds ratios with 95% confidence intervals were calculated for univariate and multiple regression models and a significance level of 5% was used. Recruitment site (hospital) was included in the multiple regression analysis to control for between site differences in patient characteristics. Analyses were undertaken using STATA version 11.2.

Sample size

This study aimed to recruit a total of 450 patients from four hospital sites, which would allow us to obtain prevalence estimates with 95% CIs with ± 5% of the point estimate. This sample size would also allow us to detect differences of 15% in characteristics between the groups who opt-in and who opt-out of the life expectancy section with a 5% significance level and 80% power.
1.4 Results

Of the 785 patients screened for eligibility, 126 did not meet the eligibility criteria. Of the 659 patients who were invited to join the study, 570 (86%) consented to participate in the survey, of whom 82% ($n = 469$; 71% of all eligible participants) completed the survey in its entirety. Data was not available for participants who consented but were unable to complete the survey due to time limitations. Participants were 242 males and 227 females, with a mean age of 61.5 years (SD = 13.2, Median = 62.9, Q1, Q3: 52.4, 70.2). At the time of recruitment, respondents were a mean of 85.8 weeks since diagnosis (SD = 169.1, Median = 28.7, Q1, Q3: 16.2, 57.2), and had attended a mean of 11.6 outpatient radiation therapy appointments (SD = 10.2, Median = 9, Q1, Q3: 4, 18). Respondents reported that their most recent primary cancer diagnosis was breast (28%), prostate (22%), head and neck (9.6%), colorectal (bowel) (5.3%), brain (4.3%), lung (4.0%), melanoma (3.4%), non-Hodgkin lymphoma (3.2%), other cancers (17%), and 2.1% did not know. Sixty-nine percent of respondents were Australian born.

Three hundred and twenty-seven (70%, 95% CI, 65%, 74%) of the 469 participants who completed the survey indicated that they were willing to answer questions about life expectancy. Overall, this meant that 50% of all eligible participants completed the survey questions about life expectancy. Table 1.1 outlines the results of the univariate and multiple logistic regression analysis assessing characteristics associated with willingness to complete the life expectancy questions. Following univariate analysis, clinically significant anxiety ($p = 0.3$) and perceived palliative treatment aim ($p = 0.5$) were excluded from the model (see Table 1.1). Remaining variables entered into the multiple logistic regression analysis included age group, gender, cancer type, region of birth and depression. Compared to the youngest age group (18-49 years) those aged 60-69 years and 70 years or more had significantly lower odds of answering the life
expectancy questions (see Table 1.1). Females had significantly lower odds of answering the life expectancy questions than males. Participants born in Asia had lower odds of answering the life expectancy questions than Australian born participants, and a similar trend was seen for European born participants (although marginally non-significant). Compared to participants with breast cancer, participants with "other cancers" (i.e. not breast or prostate cancer) had significantly lower odds of completing the life expectancy questions. Having clinically significant depression according to the HADS was not found to be significantly associated with the outcome of interest in the multiple regression model.
Table 1.1: Univariate and multiple logistic regression of characteristics of 469 participants completing the patient views survey

<table>
<thead>
<tr>
<th>Variables</th>
<th>Willing to complete life expectancy questions n (row %)</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
<th>Likelihood ratio χ²(df), p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>121 (70%)</td>
<td>1</td>
<td>1</td>
<td>4.0 (3), p = 0.2663</td>
</tr>
<tr>
<td>Site 2</td>
<td>90 (65%)</td>
<td>0.8 (0.4-1.2)</td>
<td>0.8 (0.5-1.3)</td>
<td></td>
</tr>
<tr>
<td>Site 3</td>
<td>51 (68%)</td>
<td>0.9 (0.5-1.6)</td>
<td>1.0 (0.5-1.9)</td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td>65 (77%)</td>
<td>1.4 (0.8-2.6)</td>
<td>1.5 (0.8-2.8)</td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49</td>
<td>72 (77%)</td>
<td>1</td>
<td>1</td>
<td>10.7 (3), p = 0.0137</td>
</tr>
<tr>
<td>50-59</td>
<td>73 (72%)</td>
<td>0.7 (0.4-1.4)</td>
<td>0.6 (0.3-1.3)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>104 (68%)</td>
<td>0.6 (0.3-1.1)</td>
<td>0.4 (0.2-0.8)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>78 (64%)</td>
<td>0.5 (0.3-1.0)</td>
<td>0.4 (0.2-0.7)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>179 (74%)</td>
<td>1</td>
<td>1</td>
<td>13.9 (1), p = 0.0002</td>
</tr>
<tr>
<td>Female</td>
<td>148 (65%)</td>
<td>0.7 (0.4-1.0)</td>
<td>0.3 (0.2-0.6)</td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Willing to complete life expectancy questions</td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Likelihood ratio $\chi^2$(df), $p$</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------</td>
<td>------------------------</td>
<td>----------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td></td>
<td>$n$ (row %)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unadjusted</td>
<td>Adjusted</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Region of birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>237 (73%)</td>
<td>1</td>
<td>1</td>
<td>10.8 (4), $p = 0.0291$</td>
</tr>
<tr>
<td>UK and Ireland</td>
<td>26 (67%)</td>
<td>0.7 (0.4-1.5)</td>
<td>0.7 (0.3-1.4)</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>19 (58%)</td>
<td>0.5 (0.2-1.0)</td>
<td>0.4 (0.2-0.8)</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>20 (57%)</td>
<td>0.5 (0.2-1.0)</td>
<td>0.5 (0.2-1.0)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>25 (66%)</td>
<td>0.7 (0.3-1.4)</td>
<td>0.5 (0.2-1.1)</td>
<td></td>
</tr>
<tr>
<td>Palliative treatment aim</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>43 (73%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>263 (69%)</td>
<td>1.2 (0.7-2.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>99 (74%)</td>
<td>1</td>
<td>1</td>
<td>13.4 (2), $p = 0.0012$</td>
</tr>
<tr>
<td>Prostate</td>
<td>79 (75%)</td>
<td>1 (0.6-1.9)</td>
<td>0.5 (0.2-1.1)</td>
<td></td>
</tr>
<tr>
<td>Other a</td>
<td>149 (65%)</td>
<td>0.6 (0.4-1.0)</td>
<td>0.3 (0.2-0.6)</td>
<td></td>
</tr>
</tbody>
</table>

* Other includes all other cancer types not specified as breast or prostate.
<table>
<thead>
<tr>
<th>Variables</th>
<th>Willing to complete life expectancy questions</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
<th>Likelihood ratio $\chi^2$(df), $p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinically significant anxiety</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>44 (58%)</td>
<td>0.8 (0.4-1.3)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>281 (70%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clinically significant depression</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td>1.0 (1), $p = 0.3151$&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Yes</td>
<td>15 (65%)</td>
<td>0.6 (0.3-1.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>310 (71%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Observations within each variable may not add to the total due to missing values

<sup>a</sup> Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types

<sup>b</sup> Assessed using the Hospital Anxiety and Depression Scale

<sup>c</sup> Eliminated during backwards stepwise multiple logistic regression analysis
1.5 Discussion

In the current study, 70% of participants who completed the survey (and 50% of all eligible patients) were willing to answer a subset of questions about their life expectancy. Previous research into patients’ preferences for life expectancy information has yielded similar consent rates. A large USA-based interview study achieved a consent rate of approximately 70% when assessing the views of 638 advanced cancer patients (recruited from outpatient clinics at seven hospital sites) about whether end of life care discussions had occurred [18]. Australian survey research into cancer patients’ prognostic communication preferences have obtained consent rates of 61% [19], while interview/focus group studies with palliative care patients have obtained consent rates of up to 83% [20]. However, recruitment for these studies was conducted through oncologists or palliative care services, and poor consent rates among oncologists or community nurses may have introduced response bias [19].

Our findings indicating that older participants had lower odds than younger participants of answering questions about life expectancy appear to be consistent with past research. Kaplowitz and colleagues [11] found that older people were significantly less likely to request and to be given prognosis information. Similarly, a review by Fujimori and colleagues reported that younger patients were more likely to express a desire for more prognosis information than older patients [5]. Younger patients may be more likely to have dependent children and be willing to discuss life expectancy information for planning purposes [21]. This may also reflect changes in patient attitudes, preferences, and expectations over time towards increased involvement in cancer treatment decision making [22].
The increased willingness to answer questions on life expectancy among males was contrary to our expectations. It has been reported that women diagnosed with cancer are more likely to want more detailed general information about cancer than men [10]. A study of response rates to an epidemiological survey involving 25,000 participants found that consent to review medical records higher in males older than 50 than females over 50 [23]. Other research has found that men were significantly more likely to be given a quantitative life expectancy estimate than women [11]. Taken together, these findings may suggest that males are more likely to be willing to be involved in research about personal or potentially sensitive issues than females.

Our findings showed that Australian-born participants had higher odds of completing life expectancy questions than respondents born in the Asian region, and marginally non-significantly higher odds than those born in Europe. Previous reports have indicated that culture may influence patients' preferences for information about life expectancy prognosis discussions [5]. A recent review of patients' preferences for life expectancy communication reported that studies conducted in Asian countries have reported that fewer than 30% of patients wish to know about life expectancy, while approximately 60% of Westerners do [4, 5]. Regional variations in physician views and practices surrounding disclosure of palliative illness status in Europe, Latin America, and Canada have also been reported [24]. These differences may be related to beliefs about the potential impact that awareness of a poor life expectancy estimate may have on patient hope, and consequentially on outcomes. Therefore, the present findings may be reflective of cultural attitudes towards discussion of life expectancy. However, a recent qualitative study looking at communication preferences in migrants to Australia with Greek-, Arabic-, and Chinese-speaking backgrounds, suggests that these migrant groups are possibly more likely than Anglo Australian patients to prefer to have access
to prognostic information [25]. It may be that a willingness to answer questions about life expectancy is not comparable to a patient preference to have access to prognostic information. It is also possible that responses regarding willingness to answer life expectancy questions in the current study may have been influenced by family members who may have been accompanying them in the waiting room during survey completion. Further exploration of discordance between patient and family preferences may be warranted in Australian and international settings. However, it does seems likely that some level of cultural variation in patient preferences for answering life expectancy questions exists and further exploration of how this relates to patients’ preferences for life expectancy disclosure may be warranted. This is particularly pertinent given that individuals without adequate English language to complete the survey were excluded from this study. Future studies should extend these findings to culturally and linguistically diverse communities [25].

Prior research has indicated that patients who identified themselves as having a shorter survival time may be less likely to want, request, and receive life expectancy information compared to those perceiving longer survival time [11]. It has also been suggested that an increased physical burden of cancer may be associated with a preference to have less involvement in cancer care decision making [10]. The current study found no association between patients’ perceived treatment aim and willingness to answer the life expectancy questions. However, individuals in the present study diagnosed with cancers with high 5-year survival rates (i.e., breast or prostate) [1] were more willing than those with other cancers to complete life expectancy questions. It is possible that the greater willingness among breast and prostate cancer patients was linked to perceived length of life. This would appear consistent with the findings of Kaplowitz and colleagues [11]. For instance, increased rates of distress in some poorer
prognosis cancer types such as of the lung and brain have been suggested to be associated with feelings of “doom” [26]. This finding warrants further exploration, as the preferences of patients with less common cancers tend to be under reported in current consensus guidelines.

**Limitations**

This research compared the characteristics of survey participants who were and were not willing to answer a subset of questions about their life expectancy. However, as part of the consent process potential participants were made aware of the optional section about life expectancy, and potential respondents (for whom demographic information is not available) may have opted out at this point. Additionally, although the current study achieved high consent rates to the initial survey (87%), only 70% of all eligible patients completed the entire survey in the time available. Once again, demographic information is not available for participants with incomplete surveys, meaning comparisons between survey completers and non-completers are not possible. Given that 70% of eligible participants completed the survey in its entirety and 70% of these respondents were willing to answer questions about their life expectancy, overall, 50% of all eligible participants completed the life expectancy questions. Although this overall consent rate is comparable to other research [27], it may limit the external validity of the study results.

All patient demographic and disease data was collected via patient self-report, meaning accuracy for some items may be questioned [28]. Accuracy of self-reported cancer history validated against medical records and cancer registry data has been found to be high [29], with high sensitivity in cancer outpatient samples [30].
Implications

There remains a need for high-quality research in the area of life expectancy communication. However, this research needs to minimize the risk of psychological distress to patients while also maximizing the representativeness of samples consulted. This approach to empowering patients to decide whether or not to answer research questions of this nature, rather than having access to patients restricted by clinical gatekeepers, requires a balancing of the ethical principles of beneficence and autonomy [31]. The current study found high consent rates to both the initial survey and also to the life expectancy questions embedded within the main survey, which resulted in an overall acceptable consent rate. This suggests that this patient-centered approach to researching this sensitive topic was both feasible and acceptable, but the degree of acceptability varied across different subgroups. Further research may be needed to identify how to improve acceptability of this research to subgroups including those who are female, aged 60 years or over, diagnosed with less common cancer types, and Australian migrants from Asian regions [5, 22].

Conclusions

Giving cancer patients the opportunity to opt out of questions about a sensitive issue is a feasible and acceptable option for accessing important information about patient preferences. This method also promotes greater autonomy than clinician-determined methods of access to patients for these types of surveys. Further research may be needed to identify approaches to improve acceptability of research on life expectancy discussions with cancer patients who are older, female, diagnosed with less common cancer types, and who are born in Asia.
Acknowledgements

We would like to thank Dr. Patrick McElduff, Mr. Daniel Barker and Mr. Michael Fitzgerald for their assistance with statistical analysis. Mr. Sundresan Naicker, Ms. Kelauren Barry, Ms. Jay Roberts, and Mr. Ryan Courtney all assisted with data collection. We would also like to thank the staff and patients at the participating radiation oncology treatment centers. Lisa Mackenzie’s PhD candidature is supported by The University of Newcastle School of Medicine and Public Health Professor Jill Cockburn Scholarship in Health Behaviour. Dr. Mariko Carey is supported by a Hunter Medical Research Institute (HMRI) Post Doctoral Fellowship. The touch screen computer resources and patient recruitment costs were covered by a 2009 University of Newcastle Priority Research Centre for Health Behaviour research grant.

Conflict of interest

No authors have reported financial relationships with research sponsoring organizations. Miss Lisa Mackenzie, the corresponding author, had and has full control of the primary data. The authors agree to allow Supportive Care in Cancer to review the data, if requested.
1.6 References


PAPER TWO

Do we get it right? Radiation oncology outpatients’ perceptions of patient centredness of life expectancy disclosure

As described in Paper One, participants in a large cross-sectional study of cancer care were asked if they were additionally willing to complete questions about communication of life expectancy. Paper Two reports on data from a subsample of the respondents in Paper One who completed the life expectancy questions. Paper Two describes the proportion of radiation oncology outpatients who reported that discussions about life expectancy were consistent with their preferences. We also explored whether there were particular socio-demographic and disease characteristics associated with radiation oncology outpatients who perceived that their experiences of life expectancy discussions were aligned with their preferences (i.e. that life expectancy disclosure was patient-centred) [1-3].

This paper was published in Psycho-oncology (see Appendix 2.1).

References


Do we get it right? Radiation oncology outpatients’ perceptions of the patient centredness of life expectancy disclosure

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2. Hunter Medical Research Institute, Newcastle, Australia
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2.1 Abstract

Objective
A patient centred approach to discussing life expectancy with cancer patients is recommended in Western countries. However, this approach to eliciting and meeting patient preferences can be challenging for clinicians. The aims of this study were a) to examine cancer patients’ preferences for life expectancy disclosure, and b) to explore agreement between cancer patients’ preferences for, and perceived experiences of, life expectancy disclosure.

Methods
Cancer patients undergoing radiotherapy treatment in metropolitan Australia completed a cross-sectional touchscreen computer survey including optional questions about their life expectancy disclosure preferences and experiences.

Results
Of the 208 respondents, 178 (86%) indicated they would prefer their clinician to ask them before discussing life expectancy, and 30 (14%) indicated that they would prefer others (i.e. clinicians, family) to decide whether they were given life expectancy information. Of 175 respondents who were classified as having a self- or other-determined disclosure experience, 105 (60%) reported an experience of life expectancy disclosure that was in accordance with their preferences. Cohen’s \( \kappa \) was -.04 (95% CI: -0.17, 0.08), indicating very poor agreement between patients’ preferences for and perceived experiences of life expectancy disclosure (\( p = 0.74 \)).

Conclusions
In light of patient-centred prognosis disclosure guidelines, our findings of a majority preference for, and experience of, a self-determined approach to life expectancy disclosure...
disclosure amongst radiation oncology patients are encouraging. However, poor agreement between preferences and experiences highlights that additional effort from clinicians is required in order to achieve a truly patient centred approach to life expectancy disclosure.

*Keywords:* cancer, oncology, patient centred care, patient preference, prognosis, radiotherapy
2.2 Introduction

What is a patient centred approach to life expectancy disclosure?

Many cancer patients, particularly those in Western countries, report concerns and unmet needs relating to cancer prognosis information and communication [1-3]. Western consensus guidelines for prognosis disclosure to cancer patients are in keeping with a patient centred approach to healthcare [4, 5], which argues that patients’ needs, values and preferences should be dominant when negotiating prognosis disclosure [6]. A patient centred approach requires that the patient and clinician have an explicit understanding of the patient’s preferences for disclosure [7]. It is recommended that cancer clinicians commence a prognosis discussion by asking patients “How much do you want to know about your prognosis?” [4, 8, 9]. This approach also gives patients the “right not to know” about their life expectancy if they prefer [10], as some cancer patients do not want life expectancy information [11]. These guidelines are based on a combination of expert consensus and descriptive research on patient preferences and experiences [4, 5, 12-14].

How can we assess whether disclosure practices are aligned with patient centred guidelines and with patient preferences?

There are a variety of useful methods that can be employed to assess patient-clinician communication in cancer care [15], including patient self-report, carer self-report, clinician self-report, audiotaped/recorded observation and medical records [16, 17]. The quality of prognosis communication should not be assessed by whether or not information was provided, but by whether it was given in a way that patients can understand, recall and use to make informed decisions about their healthcare [11].

Research into patient preferences for life expectancy communication has focused on heterogeneous samples of early and advanced stage cancer patients [18]. However,
research into patients' perceived experiences of life expectancy disclosure is largely based on samples of advanced or metastatic cancer patients [19], patients diagnosed with breast cancer or melanoma [20, 21], and patients diagnosed with life limiting diseases other than cancer [11, 22]. Kaplowitz and colleagues examined concordance between patients' preferences and experiences of prognosis disclosure in the USA; however, limitations of this study included a low response rate, and a sample comprised mostly of females with a previous breast cancer diagnosis (but reporting being cancer free at the time of the study) [23]. To explore the degree to which patient-centred life expectancy disclosure is occurring in clinical practice, there remains a need to explore the concordance between preferences for and perceived experiences of the initiation of life expectancy disclosure amongst a heterogeneous sample of both early and advanced stage cancer patients. This will help to clarify whether current guidelines are consistent with patient preferences, as well as assess the degree to which these patients’ preferences are aligned with their experiences of the initiation of life expectancy disclosure.

Consensus guidelines recommend that clinicians should consider raising the topic of prognosis (including life expectancy) in a range of circumstances, including when patients need to make a decision about treatment [5]. It is recommended that over 50% of cancer patients in Western countries should receive radiation therapy [24]. It would be expected that clinicians may have raised the topic of life expectancy in order to obtain patients’ informed consent for radiotherapy treatment. Therefore, this study focuses on cancer patients receiving radiotherapy.
Aims and hypotheses

The aims of this study were a) to examine cancer patients' preferences for who determines whether life expectancy information is disclosed, and b) to explore the level of agreement between cancer patients' preferences for, and experiences of, the disclosure of life expectancy information. We hypothesised that patients would prefer to make the decision themselves about whether life expectancy information is disclosed to them, and that this preference would align with patient self-reported experiences of clinical practice [4, 5, 12, 14]. We also aimed to assess disease and demographic factors associated with a patient perception that their preferences for life expectancy disclosure had been met. It was expected that perceived patient centred communication may be influenced by socio-demographic and disease characteristics including sex [25], age, region of birth, living arrangement, cancer type [26-29], experience of a second diagnosis or recurrence, perceived treatment aim [30], anxiety and depression [31]. It was also expected that an increased opportunity to communicate (possibly resulting from continuing care in the same hospital or with the same doctor) may influence patient perceptions. Therefore we also explored whether the number of doctor appointments attended and years since diagnosis were associated with a perception of patient centred communication [32].

2.3 Materials and methods

Ethics approvals

Appropriate approvals were obtained from the University of Newcastle and the NSW Population & Health Services Research Ethics Committees.
Patients

Eligibility criteria

Patients aged 18 years or older, receiving adjuvant or palliative outpatient radiation therapy treatment for cancer at one of the four radiation therapy departments, and with sufficient English to complete the survey.

Exclusion criteria

Patients who were physically or mentally incapable of completing the survey or who were not currently receiving radiotherapy were excluded by clinic staff.

Setting

The study was conducted in four Australian metropolitan public hospital radiation therapy departments between July and December 2010. Recruitment periods were staggered across the sites as follows: Site 1 (August, September); Site 2 (July, September, October); Site 3 (October; December); and Site 4 (December).

Procedure

Patients waiting for radiation therapy treatment were approached by a trained research assistant, who explained the study purpose and then sought informed consent (taken by survey completion) from eligible patients. The research assistant briefly explained the survey navigation process to consenting patients, and commenced the survey by entering the patients’ unique identification number. Touchscreen computer data collection strategies in oncology settings have previously been found to be acceptable to cancer patients [33].

Measures

The patient “Cancer Care Survey” was programmed using Digivey survey software (CREOSO Corporation, Phoenix, Arizona, USA), and administered using a
touchscreen laptop computer. The survey explored patients’ views of the cancer care they had received, including their perceptions of quality of care [34], psychological characteristics and survey acceptability [35]. Participants were asked to indicate whether or not they were willing to complete questions about their life expectancy. Findings related to characteristics of individuals who were willing to answer these questions are reported elsewhere [36]. A subsample of consecutive respondents who indicated that they were willing to answer questions about their life expectancy were also asked to complete the following questions.

Preferences for self-determined disclosure of life expectancy information

Participants were asked to indicate their level of agreement with the statement, “When discussing life expectancy, I would prefer my doctor to ask me if I want to discuss life expectancy” on a 4-point Likert Scale (1 = Strongly disagree; 2 = Disagree; 3 = Agree; 4 = Strongly agree). A preference for self-determined disclosure of life expectancy information was indicated by an “agree” or “strongly agree” response to this question.

Experiences of life expectancy discussions

Respondents were asked to indicate (Yes/No) to the lead question, “Have you discussed your life expectancy with your cancer doctor?” If the response to the lead question was “yes” respondents were asked, “How did the discussion begin?” If the response to the lead question was “no”, respondents were asked, “Would you like to talk to your cancer doctor about your life expectancy?” and if “yes”, “Why haven’t you discussed your life expectancy with your cancer doctor?”

Independent variables

Demographic characteristics

In the first section of the survey, respondents were asked to report their sex, date of birth, country of birth, living arrangement (whether they live with their
husband/wife/partner; children/step-children, other family, friends, unrelated flatmates/cotenants or alone) and postcode of usual place of residence.

**Disease characteristics**
Respondents reported their cancer type, month and year of diagnosis, if they had experienced a second cancer diagnosis or a cancer recurrence, and their perceived treatment aim (to cure the cancer; to prevent the cancer coming back; to control symptoms of the cancer [cure is not possible]). They were also asked to indicate the number of radiotherapy appointments and appointments with their cancer doctor that they had attended.

**Psychological characteristics**
After the life expectancy questions, respondents completed the 14-item patient self-report Hospital Anxiety and Depression Scale (HADS) to assess the level of anxiety and depression experienced by patients in the week preceding survey completion [37]. This scale has been found to be an effective indicator of psychological distress in cancer patients undergoing treatment [38]. Patients meeting or exceeding HADS anxiety and HADS depression subscale scores of 11 are classified with likely anxiety and depression, respectively [39].

**Statistical analysis**
Patient preferences were coded into a dichotomous variable (patient self-determined disclosure of life expectancy information versus other-determined disclosure of life expectancy information). Patient experience data was similarly coded. The percentage of patients preferring self-determined disclosure of life expectancy information was estimated with 95% confidence interval (CI). Cohen's κ was used to assess whether the agreement between patient's preferences for, and experiences of, disclosure of life expectancy information was greater than expected by chance. The observed
percentage of agreement and Cohen's κ were estimated with 95% CIs, and extent of agreement between patients’ preferences and experiences was assessed amongst those classified as having a self- or other-determined disclosure experience [40]. Those who were not able to be classified into these categories of disclosure experience were excluded from further analysis. McNemar’s test was used to assess marginal homogeneity. Univariate and multiple logistic regression analysis was used to examine variables expected to be associated with a patient perception that their preferences for life expectancy disclosure had been met: sex [25]; age (calculated using date of birth and date of survey completion); region of birth (classified from self-reported country of birth); living with a partner; cancer type [26-29]; experience of a second diagnosis or recurrence; perceived palliative treatment aim [30]; HADS classified likely anxiety and depression [31]; number of doctor appointments; and approximate time since diagnosis (number of years calculated from patient self-reported year and month of diagnosis and date of survey completion) [32]. Recruitment site (hospital) was included in the multiple regression analysis, along with variables with a univariate analysis $p$ value of 0.2 or less. The backward stepwise method was then used to remove variables with a $p$-value of 0.1 or greater on the likelihood ratio test. Odds ratios with 95% confidence intervals are reported. Analysis was conducted using STATA Version 11.2 (StataCorp LP, College Station, Texas, USA) and a significance level of 5%.

Sample size

A total of 200 patients completing the life expectancy questions would allow us to obtain prevalence estimates with 95% CIs within ±7% of the point estimate (assuming approximately 60% of patients will prefer self-determination), and an estimate of kappa with 95% CIs within ±15% (assuming kappa of 0.5 or more). This sample size would also allow detection of differences in characteristics of 20% for binary explanatory
variables and 0.4 standard deviations for continuous explanatory variables (between patients whose perceived life expectancy disclosure experience did and did not meet their preference), with 5% significance level and 80% power.

2.4 Results

Response rate

Of the 529 patients screened for eligibility (based on availability of clinic staff, research assistants and touchscreen computers), 98 were recorded as being ineligible. Primary reasons for ineligibility included having inadequate English (n = 45; 8.5%) and not being a current radiotherapy patient (n = 29; 5.5%). Of the 431 eligible patients, 370 (86%) agreed to participate in the survey, and 307 (83%) completed the survey, meaning that overall 71% of eligible patients provided complete data. There was a significantly larger proportion of male non-consenters than female non-consenters (p = 0.03). Sixty-eight percent (n = 208) of participants additionally agreed to complete the optional life expectancy survey component. The individuals who completed the life expectancy component will hereafter be referred to as respondents. Respondents were an average age of 61.1 years (SD = 13.4). The most common cancer types were breast (28%), followed by prostate (25%) and head and neck cancer (9.1%). Table 2.1 shows additional disease and demographic characteristics of the sample.

Preferences for disclosure

Of the respondents, 178 (86%; 95% CI: 80%, 90%) had a preference for self-determined life expectancy disclosure decision making. Demographic characteristics of these 178 respondents are presented in Table 2.1.
Perceptions of life expectancy disclosure

Figure 2.1 shows the response pathways leading to classification as a perceived self-, other-determined or unclassified disclosure experience, the numbers of respondents following each pathway, and disclosure preferences amongst each group. Table 2.2 shows the proportion of respondents reporting experiences of life expectancy disclosure aligned with their preferences. Of the 175 respondents classified in Figure 2.1 as having a patient- or other-determined life expectancy disclosure experience, 105 (60%; 95% CI: 52%, 67%) experienced life expectancy disclosure practices aligned with their preferences. Cohen's κ was -0.04 (95% CI: -0.17, 0.08). This indicated poor agreement between respondents’ preferences for and experiences of life expectancy disclosure which was not significantly greater than expected by chance (Z = -0.65, p = 0.74). For this population, there was a difference between the experiences of individuals who preferred other-determined and those who preferred self-determined disclosure of life expectancy information. Those with a preference for other-determined life expectancy disclosure were less likely to experience disclosure in line with their preferences than those with a preference for self-determined disclosure decision making (McNemars test $\chi^2 (1) = 16.5, p < 0.0001$).

Of the 150 respondents who indicated a preference for self-determined life expectancy disclosure decision making, 98 (65%, 95% CI: 57%, 73%) perceived that their experiences of life expectancy disclosure were aligned with their preferences. Of the 25 respondents indicating a preference for other-determined life-expectancy disclosure decision making, 7 (28%, 95% CI: 12%, 49%) reported that their experiences aligned with their preferences.
Variables associated with a perception that disclosure preferences were met

Females had 3.0 times the odds of males of having a perception that their preferences for life expectancy disclosure were met (95% CI: 1.6, 5.9), $\chi^2 (1) = 11.4$, $p = 0.0007$).

The odds of perceiving that disclosure preference had been met was found to increase by 20% per additional year since diagnosis (95% CI: 1.0, 1.4), $\chi^2 (1) = 6.3$, $p = 0.0119$).
Figure 2.1: Method of classification of cancer patient perceptions of life expectancy disclosure into patient self-determined or other-determined categories

*This may have occurred without an explicit understanding between patient and clinician, therefore may not have been truly patient determined.*
Table 2.1: Demographic and disease characteristics of respondents and proportion with a preference for self-determined disclosure (n = 208)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>Preference for self-determined disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (row %)</td>
<td>n (column %)</td>
</tr>
<tr>
<td></td>
<td>208</td>
<td>178 (86%)</td>
</tr>
<tr>
<td>Age category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49</td>
<td>48 (23)</td>
<td>43 (90)</td>
</tr>
<tr>
<td>50-59</td>
<td>42 (20)</td>
<td>38 (90)</td>
</tr>
<tr>
<td>60-69</td>
<td>65 (31)</td>
<td>59 (91)</td>
</tr>
<tr>
<td>70+</td>
<td>53 (25)</td>
<td>38 (72)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>115 (55)</td>
<td>95 (83)</td>
</tr>
<tr>
<td>Female</td>
<td>93 (45)</td>
<td>83 (89)</td>
</tr>
<tr>
<td>Region of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>148 (71)</td>
<td>125 (84)</td>
</tr>
<tr>
<td>UK and Ireland</td>
<td>19 (9.1)</td>
<td>16 (84)</td>
</tr>
<tr>
<td>Continental Europe</td>
<td>15 (7.2)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>Asia</td>
<td>11 (5.3)</td>
<td>11 (100)</td>
</tr>
<tr>
<td>Other</td>
<td>15 (7.2)</td>
<td>15 (100)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34 (17)</td>
<td>32 (94)</td>
</tr>
<tr>
<td>No</td>
<td>167 (83)</td>
<td>140 (84)</td>
</tr>
<tr>
<td>Second diagnosis or recurrence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63 (32)</td>
<td>53 (84)</td>
</tr>
<tr>
<td>No</td>
<td>136 (68)</td>
<td>117 (86)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>59 (28)</td>
<td>48 (81)</td>
</tr>
<tr>
<td>Prostate</td>
<td>53 (25)</td>
<td>43 (81)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>19 (9.1)</td>
<td>18 (95)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>12 (5.8)</td>
<td>10 (83)</td>
</tr>
</tbody>
</table>
## Characteristic

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Preference for self-determined disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (row %)</td>
<td>n (column %)</td>
</tr>
<tr>
<td>Lung</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hodgkin’s lymphoma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Melanoma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10 (4.8)</td>
<td>8 (80)</td>
</tr>
<tr>
<td></td>
<td>7 (3.4)</td>
<td>6 (86)</td>
</tr>
<tr>
<td></td>
<td>6 (2.9)</td>
<td>6 (100)</td>
</tr>
<tr>
<td></td>
<td>6 (2.9)</td>
<td>6 (100)</td>
</tr>
<tr>
<td></td>
<td>32 (15.4)</td>
<td>30 (94)</td>
</tr>
<tr>
<td></td>
<td>4 (1.9)</td>
<td>3 (75)</td>
</tr>
</tbody>
</table>

### Likely anxiety a

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>27 (13)</td>
<td>26 (96)</td>
</tr>
<tr>
<td>No</td>
<td>179 (89)</td>
<td>150 (84)</td>
</tr>
</tbody>
</table>

### Likely depression a

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9 (4.4)</td>
<td>9 (100)</td>
</tr>
<tr>
<td>No</td>
<td>197 (96)</td>
<td>167 (85)</td>
</tr>
</tbody>
</table>

### Living with b

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband/wife/partner</td>
<td>141 (68)</td>
<td>120 (85)</td>
</tr>
<tr>
<td>Children/stepchildren</td>
<td>38 (18)</td>
<td>32 (84)</td>
</tr>
<tr>
<td>Other family</td>
<td>14 (67)</td>
<td>13 (93)</td>
</tr>
<tr>
<td>Friend/s</td>
<td>5 (2.4)</td>
<td>4 (80)</td>
</tr>
<tr>
<td>Unrelated flatmate/co-tenant</td>
<td>2 (1.0)</td>
<td>2 (100)</td>
</tr>
<tr>
<td>Alone</td>
<td>39 (19)</td>
<td>33 (85)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Median (Q1, Q3)</th>
<th>Median (Q1, Q3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of radiation treatments</td>
<td>8.5 (4, 15)</td>
<td>9 (4, 16)</td>
</tr>
<tr>
<td>Number of appointments with cancer doctor</td>
<td>3.4 (2, 4)</td>
<td>3 (2, 4)</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>0.6 (0.3, 1.4)</td>
<td>0.6 (0.3, 1.5)</td>
</tr>
</tbody>
</table>

Numbers may not add up to total due to missing data. Due to rounding, percentages may not add up to total.

a Determined as meeting or exceeding a HADS subscale threshold score of 11.

b The first five categories were not mutually exclusive, so percentage exceeds 100%.
Table 2.2: Proportion of patients reporting experiences of life expectancy disclosure in alignment with preferences ($n = 175$)

<table>
<thead>
<tr>
<th>Patient preference</th>
<th>Patient experience</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self-determined disclosure</td>
<td></td>
</tr>
<tr>
<td>Self-determined disclosure</td>
<td>98 (65%) $^a$</td>
<td>150</td>
</tr>
<tr>
<td>Other-determined disclosure</td>
<td>52 (35%) $^a$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>116</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other-determined disclosure</td>
<td></td>
</tr>
<tr>
<td>Other-determined disclosure</td>
<td>18 (72%) $^a$</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>7 (28%) $^a$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>59</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>175</td>
</tr>
</tbody>
</table>

$^a$Row percentages

2.5 Discussion

Preferences for life expectancy disclosure

The majority of respondents (86%) preferred that their cancer doctor ask them before discussing the impact that cancer might have on their life expectancy. Respondent preferences are closely aligned with consensus guidelines for a patient centred approach to disclosure. It should be noted that within the bounds of previous findings (2-38%)[41, 42], a minority of respondents (14%) preferred life expectancy disclosure decisions to be made by others (e.g. clinicians, partners, family members).

Characteristics of the sample with a preference for self-determined disclosure were presented, but not formally tested due to the small proportion of patients with a preference for other-determined disclosure. It has been suggested that this preference for other-determined disclosure may vary due to cultural factors [43] and to variations in individual coping style or adjustment [44]. A preference for other-determined disclosure of life expectancy information does not appear to be compatible with the recommended patient centred approach, making it difficult for clinicians to navigate an appropriate approach to disclosure for these individuals [7] within the context of shared decision
making, patient confidentiality and autonomy [45, 46]. Guidelines currently acknowledge this dilemma [5, 18].

Although the aforementioned minority preference for other-determined initiation of life expectancy disclosure poses a dilemma for clinicians [41, 42, 47], improving clinician adherence to the recommended patient centred prognosis disclosure practice would increase responsiveness to the majority preference for self-determined disclosure. Recent reviews have identified some factors that may be associated with a preference for other-determined disclosure (i.e. older age, male sex, low levels of distress and anxiety, and a family-centred cultural background) [43]. However, assessment of patient preferences at the level of the individual is still crucial [5, 48]. A potential way forward for clinicians may be to explore early on whether patients would prefer a) their clinician to take responsibility for initiating a life expectancy discussion when they view it as important or b) to take responsibility themselves for initiating a life expectancy discussion if and when they want this information [49].

**Agreement between respondents’ preferences and experiences**

In the present study, only 60% of the respondents reported experiences of life expectancy disclosure aligned with their preferences. Kaplowitz and colleagues reported that 73% of their sample had received quantitative life expectancy estimates in accordance with their preferences [23]. It should be noted that the Kaplowitz study assessed whether patients wanted information about how long they might live [23], whilst the present study more specifically assessed patients' preferences for initiation of life expectancy discussions. Additionally, the present study was more representative of gender and patients undergoing treatment close to time of diagnosis than the Kaplowitz study [23]. Our findings also suggest that respondents who express a preference for other-determined disclosure are more likely to report that they miss out on receiving their preferred disclosure approach in clinical practice. This suggests that
although there has been a shift toward guideline recommended patient self-determined prognosis disclosure practices, there is still room for improvement to achieve truly patient centred care.

Factors associated with a perception that preferences for disclosure were met

Despite having a smaller sample size than planned available for analysis, the current study identified higher odds of a respondent perception that their preferences for life expectancy disclosure had been met (i.e. that life expectancy disclosure was patient-centred) for females compared to males, and for individuals with a longer versus shorter time since diagnosis. It has previously been reported that compared with males, females are more likely to want, and ask for, information about prognosis [25, 50]. Males were more likely to be given a quantitative life expectancy estimate than females, whether or not they asked for it [23]. These factors may have contributed to the discrepancies in perceived patient centred care between males and females in the present study. As a longer time since diagnosis is likely to be associated with increased opportunities for a strengthened patient-clinician relationship, communication is likely to become more patient-centred further from the time of diagnosis [32]. However, it should be noted that clinicians are also more likely to overestimate survival in longer-term patient-clinician relationships [51]. As previous research investigating experiences of prognosis disclosure has largely focused on patients with advanced and metastatic cancer [19-21], this finding emphasises the need for improvements in patient centred prognosis disclosure to patients making treatment decisions close to the time of diagnosis.

Given the mismatch identified between respondents’ preferences and experiences for life expectancy disclosure for specific patient groups, there is a need to consider potential methods for shifting current practices towards a more patient centred approach. Targeted communication, shared decision making, and bioethics education
interventions that focus on clinical interactions with male patients and cancer patients making treatment decisions close to the time of diagnosis may be the most appropriate next steps for changing practice in this area [18, 52-54]

Limitations

The degree to which we can generalise from these findings may be limited by the lower completion rate of the life expectancy section compared to completion rates for the main survey [36]. Overall, only 48% of those eligible to participate completed the survey and the optional section on life expectancy. In our previous assessment of factors associated with opting out of these life expectancy questions, patients who were female, older, and diagnosed with cancer types other than breast and prostate had lower odds of answering the life expectancy questions [36]. There was also an association between lower odds of answering the life expectancy questions and being born in Asia [36]. It is also noteworthy that only 16% of the sample perceived that their treatment aim was palliative, whilst it has been suggested approximately 40% of radiation therapy courses are delivered with palliative intent [55]. This may reflect that some patients are not aware of the aim of their treatment, or alternatively that patients with poorer prognosis cancer types may be less likely to answer questions about life expectancy [36], or to be considered eligible for and consent to survey research in this setting. Taken together, these characteristics suggest that the study sample may have been skewed towards younger, Australian-born patients being treated with curative intent, possibly limiting generalizability of the findings. Despite these limitations, the life expectancy question completion rate of 48% reported in this study is only slightly lower than consent rates of 58% obtained in a similar Australian study [56]. The present study extends on this past research by providing valuable information about the concordance between patients’ preferences and experiences of life expectancy discussions outside advanced or metastatic melanoma or breast cancer patient populations [19-21].
Some limitations of patient self-report should also be noted. Although respondents were asked a generic question about whether they had discussed life expectancy with their "cancer doctor", conducting the survey in a radiotherapy setting may have influenced patients to only consider communications with their radiation oncologist.

Secondly, it is difficult for patients to determine whether their doctor has fully or partially disclosed information about their life expectancy following patient self-determined life expectancy discussion initiation. This may suggest that alignment of life expectancy disclosure with the preference held by the majority of respondents (self-determined disclosure) is lower than the 65% reported here. However, given that the survey respondents who opted out of the life expectancy section were probably more likely to have had a preference for other-determined disclosure, the true proportion of patients preferring self-determined disclosure may be smaller than identified in this study. This emphasises the need to broaden our understanding of what predicts patients’ preferences for life expectancy disclosure in order to support clinical decision making in this area.

We intentionally focused on patients’ perceptions of life expectancy discussions for the purposes of this study. However, future research could combine this method with more objective observational methods to assess life expectancy disclosure practices [46, 57, 58]. This could provide insight into possible reasons for non-concordance between doctors and patients regarding life expectancy communication.

**Conclusions**

Although preferences for a self-determined approach to life expectancy disclosure are consistent with clinical practice guidelines, our findings suggest that patient reported experiences in clinical practice are not always aligned with this preference. We found that males and patients with less time since their cancer diagnosis had lower odds of perceiving patient centred life expectancy disclosure. This suggests a need for targeted
interventions to assist both patients and clinicians with communication skills for bringing prognosis disclosure into alignment with the recommended patient centred approach for these patient groups.

Acknowledgements

We would like to thank Mr Sundresan Naicker, Mrs Jay House, Ms Kelauren Barry and Mr Ryan Courtney for their assistance with data collection. We would also like to express our very great appreciation to all of the staff and patients in the participating radiation oncology departments. Lisa Mackenzie’s PhD candidature is supported by The University of Newcastle School of Medicine and Public Health Professor Jill Cockburn Scholarship in Health Behaviour. Dr. Mariko Carey is supported by a Hunter Medical Research Institute (HMRI) Post Doctoral Fellowship. The touch screen computer resources and patient recruitment costs were covered by a 2009 University of Newcastle Priority Research Centre for Health Behaviour research grant. This research was also supported by a Strategic Research Partnership Grant from NSW Cancer Council to the Newcastle Cancer Control Collaborative.
2.6 References


Approximately 30% of cancer patients experience heightened levels of psychological morbidity during cancer treatment [1]. Identifying the prevalence of psychological distress in cancer patients during radiotherapy treatment is important for psychosocial service delivery planning in radiation oncology outpatient settings [2, 3]. However, only 49% to 58% of cancer patients with elevated anxiety, depression or emotional distress seek psychosocial support [4]. Identification of socio-demographic and disease characteristics that relate to elevated levels of psychological anxiety and depression may help to provide an “index of suspicion” for staff based in radiation oncology treatment centres. This may assist with identifying individuals more likely to be at risk of experiencing anxiety and depression.

There are a number of standardised instruments available for assessing anxiety, depression and psychological distress in oncology settings [5]. The Hospital Anxiety and Depression Scale (HADS) is a brief, patient self-report measure. The HADS comprises two seven-item subscales assessing symptoms of anxiety (HADS-A) and depression (HADS-D) in the week preceding administration [6, 7]. Although not recommended by the scale developers [6], the HADS total score (HADS-T) has also been used to indicate clinically significant distress [8-13]. The HADS has been widely used for psycho-oncology research purposes [13-16]. The HADS scores are comparable when administered to cancer patients using touch screen computer and pen-and-paper questionnaires [17].
Paper Three describes the prevalence of, and factors associated with, anxiety and depression in a sample of radiation oncology outpatients, and the acceptability of touch screen computer administration of a psychosocial survey to patients in a treatment centre setting.

This paper was published in *Supportive Care in Cancer* (see Appendix 3.1).

References


Psychological distress in cancer patients undergoing radiation therapy treatment

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4. Centre for Clinical Epidemiology and Biostatistics, School of Medicine and Public Health, Faculty of Health, University of Newcastle, Callaghan, New South Wales 2308, Australia
3.1 Abstract

Purpose
The objective of this study was to examine the likely presence of, and factors associated with, anxiety, depression and overall psychological distress in cancer outpatients undergoing radiation therapy treatment in Sydney, Australia.

Methods
A touchscreen computer survey was conducted in four radiation therapy treatment centre waiting rooms. Patients waiting to receive treatment completed the survey which included questions about demographic and disease characteristics, survey acceptability and the Hospital Anxiety and Depression Scale (HADS).

Results
A total of 454 patients (70%) completed the touchscreen computer survey. The likely presence of anxiety (HADS-A ≥11), depression (HADS-D ≥11) and overall psychological distress (HADS-T ≥15) was 15, 5.7 and 22%, respectively. Cancer type was found to be associated with each HADS screening category. The majority of patients reported high survey acceptability and willingness to complete similar touchscreen computer surveys in the treatment centre waiting room on additional occasions.

Conclusions
As radiotherapy patients frequently attend the radiation oncology department, routine screening and intervention for elevated levels of psychological distress in this setting appears to be feasible. High survey completion rates and high patient-rated acceptability supports this approach to screening. The likely presence of psychological distress is reported for this sample; however, the selection of HADS threshold scores is likely to have influenced the reported rates. Further research is needed to identify how cancer type impacts on likely caseness across the different HADS classifications examined.

Keywords: anxiety; depression; cancer; radiotherapy; touchscreen computers; HADS
3.2 Introduction

Cancer and assessment of psychological distress

Cancer is a leading cause of morbidity and mortality, with an estimated 12.7 million new cancer cases and 7.6 million cancer deaths worldwide in 2008 [1]. Cancer has also been associated with elevated levels of psychological distress [2-4]. Undetected and untreated psychological distress may have implications for important patient outcomes, including treatment adherence, level of self-care, length of hospital stays and service use [3, 5]. Routine screening for psychological distress in oncology settings has been recommended; however, it has not been widely adopted [6]. Further exploration of the acceptability of distress screening in clinical settings is warranted.

Why focus on radiation therapy patients?

It is recommended that approximately half of all new cancer patients should receive radiation therapy (RT) [7]. RT is usually delivered on an outpatient basis through cancer treatment centres on a Monday-Friday schedule over 2-8 weeks [8, 9]. It has been suggested that this intensive treatment period may provide a valuable opportunity for screening and intervening for psychological distress [10, 11]. Despite the large body of research on prevalence and factors associated with psychological distress in cancer patients [3, 12-14], only a small number of studies have focused on RT patients during treatment [9]. Amongst existing studies, the use of relatively small sample sizes [15, 16] and a focus on a limited range of cancer types [17] has limited the degree to which these findings can be generalised to all cancer patients undergoing RT treatment.

Why examine factors associated with poorer psychosocial outcomes in radiation oncology patients?

Identification of factors associated with poorer psychosocial outcomes in RT patients may aid the radiation oncology health care team in identifying patients who may be in need of additional psychosocial support. For instance, studies in oncology patients
have suggested that cancer patients who are younger [12, 15, 18], female [12, 18, 19], and perceive that their treatment aim is palliative [20] may be more likely to suffer from elevated levels of psychological distress. It has also been suggested that other demographic factors such as ethnicity [12, 21] and cancer type [13] may influence rates of distress. To the best of our knowledge, this is the first Australian study of psychological distress in a large, heterogeneous sample of radiation oncology outpatients who are currently undergoing treatment [9]. This study aimed to establish in a radiation oncology patient population (1) the likely presence of (a) anxiety, (b) depression and (c) overall distress using the HADS, and (2) factors associated with a likely presence of (a) anxiety, (b) depression and (c) overall distress. We also assessed the acceptability of a touchscreen computer survey conducted in RT treatment waiting rooms to investigate the likely presence of psychological distress.

3.3 Patients and methods

Design

This was a cross-sectional patient survey.

Participants

Cancer outpatients were recruited from four metropolitan RT treatment centres attached to large public hospitals in Australia between February and December 2010. Eligibility criteria included being aged 18 years or older, having a cancer diagnosis, receiving RT treatment, and understanding sufficient English to complete the patient survey.

Ethical standards

Human research ethics approvals were obtained from The University of Newcastle and the New South Wales Population and Health Services Research Ethics Committee. Research governance authorisations were also obtained from participating hospitals.
Procedure
A research assistant (RA) attended the radiation oncology departments. Patients waiting for their RT treatment were invited to participate based on the availability of the RA and touchscreen computers. Informed consent was sought from eligible patients. Consenting patients were allocated a unique identification code to login to the touchscreen computer survey, which they completed whilst waiting for their RT treatment.

The patient survey
The survey was programmed into a Dell Latitude XT2 touchscreen computer using Digivey survey software (CREOSO Corporation, Arizona). Touchscreen computer surveys assessing psychological distress and completed in an oncology waiting room have been previously found to be acceptable to cancer patients [22]. The following modules were embedded within a larger survey.

The Hospital Anxiety and Depression Scale
The Hospital Anxiety and Depression Scale (HADS) is a brief (14-item) patient self-report measure of anxiety and depression requiring respondents to report their symptoms during the previous week [23]. The HADS has demonstrated reliability and validity in cancer patient populations [24] and has been found to be an effective screening tool for cancer patients currently undergoing treatment [25]. Additionally, HADS scores have been found to be comparable when administered by touchscreen computer and pen-and-paper modes [26].

The sensitivity and specificity of the HADS are influenced by the threshold scores used to identify a likely presence of anxiety and depression [27, 28]. The HADS is divided into anxiety (HADS-A) and depression (HADS-D) subscales. Subscale scores of 0-7 are classified as normal, 8-10 as mild, 11-14 as moderate and 15-21 as severe [29]. Subscale scores ranging from 8 [24, 30] to 11 [31] are typically used for identifying the
possible presence of anxiety and depression. Cancer research has extensively applied subscale thresholds of 11 to indicate the likely presence of anxiety and/or depression, reported as achieving 70-95% sensitivity and 83% specificity [32]. Although the use of the HADS total score (HADS-T) was not recommended by the scale developers [23], recently, HADS-T scores of 10-15 have been used to indicate the likely presence of overall psychological distress. Ibbotson et al [25] found that a HADS-T threshold score of ≥15 resulted in 80% sensitivity, 76% specificity and a positive predictive value of 41% for detecting generalised anxiety disorder or major depressive illness as assessed by the Psychiatric Assessment Schedule. This HADS-T threshold has also been applied in similar studies examining cancer patients’ psychological distress.

**Demographic and disease explanatory variables**

Participant age, sex, cancer diagnosis, time since diagnosis, country of birth, and treatment aim were collected via patient self-report. Self-reported clinical information, including reporting of cancer site and time since diagnosis, in this population has been found to provide reliable when compared to cancer registry records [33].

**Acceptability of touchscreen computer survey**

A subsample of consecutive patients completed investigator-derived items assessing the acceptability of the touchscreen computer survey. Respondents were asked how much they agreed with a series of statements on a four-point Likert scale (strongly disagree, disagree, agree, and strongly agree). Statements included “The instructions were easy to follow”, “The questions were easy to understand”, “The touchscreen was easy to use”, “I had enough time to complete all the questions”, “I felt comfortable answering the questions” and “The touchscreen allowed enough privacy”. Respondents were also asked to indicate on how many visits to the treatment centre they would be prepared to complete a similar touchscreen computer survey. Response options were
Only once (just this survey), “Less than half the visits”, “Half of the visits”, “Most visits” or “Every visit”.

**Statistical analysis**

HADS-A and HADS-D subscale scores were calculated for each participant. The proportion with scores meeting or exceeding threshold scores for moderate–severe levels (≥11) on each subscale was calculated with 95% confidence interval (CI). The proportion of participants with a likely presence of psychological distress defined as total HADS threshold score of ≥15 was also reported with 95% CIs. Univariate logistic regression analyses were then used to identify factors associated with a likely presence of anxiety, depression and overall distress. Variables with a \( p \) value of 0.2 or less were included in the multiple logistic regression model. Variables examined at univariate level included age (18–49 years, 50–59 years, 60–69 years and 70 years or more), sex, country of birth (Australian born and not Australian born), cancer type (breast, prostate, other common cancer, other cancer) and perceived treatment aim (palliative and not palliative). The backward stepwise method was used to remove variables with a \( p \) value of 0.1 or greater on the likelihood ratio test [34]. Recruitment site (hospital) was included in the multiple regression analysis to account for the sampling strategy. Odds ratios with 95% confidence intervals are reported for univariate and multiple regression models, and a significance level of 5% used. The proportion of patients reporting that they agreed or strongly agreed with each of the acceptability items are also reported with 95% CIs. Analyses were undertaken using Stata version 11.2.

**Sample size**

This study aimed to invite 600 eligible patients from the four hospital sites to participate. Assuming a survey consent and completion rate of 75% this would provide 450 respondents. Based on prevalence rates previously found in oncology settings, this would allow us to obtain prevalence estimates with 95% CIs within ±3% of the point
estimate for likely anxiety and depression and ±4% of the point estimate for likely psychological distress. This sample size would also be sufficient to detect differences in characteristics between those with and without the outcome of interest of 20% for anxiety and psychological distress, and 25% for depression. Assuming 90% acceptability, a subsample of 160 patients would also allow us to obtain prevalence estimates with 95% CIs within ±5% of the point estimate for the acceptability items.

3.4 Results

Patient characteristics

Of the 785 patients screened for eligibility, 659 were considered eligible to participate and were invited to join the study. Reasons for ineligibility included inadequate English (n = 60); not currently receiving RT (n = 21); clinic staff noted ineligibility regarding inpatient status and/or in ability to give informed consent (n=13); and if the patient had already been approached about the survey (n = 6), was not diagnosed with cancer (n = 4), or was under the age of 18 (n = 2). For 13 patients, the specific reason for ineligibility was not recorded. Of the eligible patients, 570 (86%) agreed to participate. Surveys with completed HADS were obtained from 454 (70% of eligible patients) who are classified as respondents for the purposes of this study. Incomplete data generally resulted from respondents being called into their appointment before survey completion. Twelve completed surveys with responses indicating that the respondent was attending an outpatient appointment other than treatment were excluded from further analysis to fit with eligibility criteria for this study. The first 159 consecutive respondents answered the survey acceptability items.

Of the respondents, 233 (51%) were male, 221 (49%) were living with a husband, wife or partner, 98 (22%) were living with children/stepchildren, 30 (6.6%) with other family, 9 (2.0%) with friends, 6 (1.3%) with an unrelated flatmate or cotenant, 90 (20%) were living alone and 315 (69%) were born in Australia. The mean age was 61.2 years (SD
= 13.1), ranging from 18.9 to 91.4 years. Fifty-nine participants (13%) perceived that their treatment aim was palliative. One hundred and thirty-one participants (29%) were diagnosed with breast cancer, 100 (22%) with prostate cancer, 44 (9.8%) with head and neck cancer, 23 (5.1%) with colorectal (bowel) cancer, 20 (4.4%) with brain cancer, 19 (4.2%) with lung cancer, 16 (3.6%) with melanoma, 15 (3.3%) with non-Hodgkin’s lymphoma, 9 (2%) did not know and 73 (16%) had other cancer types. Respondents were a median of 28.4 weeks since diagnosis (Q1, Q3: 16.1, 55.6).

Participants identified as likely cases on the HADS-A, HADS-D and HADS-T

Sixty-eight respondents (15%; 95% CI: 11-18%) met or exceeded threshold scores for the likely presence of moderate–severe anxiety and 26 (5.7%; 95% CI 3.6-7.9%) for the likely presence of moderate–severe depression. The HADS threshold score of 15 was met or exceeded in 102 participants (22%; 95% CI: 19-27%), indicating the likely presence of psychological distress.

Factors associated with a likely presence of anxiety, depression and distress

Tables 3.1-3.3 show the initial and final multiple logistic regression models for respondents with and without a likely presence of anxiety, depression and psychological distress, respectively. As seen in Table 3.1, for HADS categorised moderate–severe anxiety, the variables age, sex and cancer type were included in the multiple logistic regression analysis. A diagnosis of prostate cancer was also associated with lower odds (0.2) of a likely presence of anxiety compared to the breast cancer reference group. Additionally, respondents in the older age category (aged 70 or above) had marginally significantly lower odds of a likely presence of anxiety compared to the youngest age group (18-49 years old).

Table 3.2 shows that for a HADS categorised likely presence of depression, age, cancer type and palliative treatment aim were included in the initial model for multiple regression analysis. Respondents diagnosed with other common cancers (including
brain, colorectal, head and neck, lung, melanoma and non-Hodgkin’s lymphoma) had 3.4 times the odds of having a likely presence of depression compared with the breast cancer reference category.

The variables age, sex and cancer type were included in the initial model for multiple regression analysis of the likely presence of psychological distress outcome (see Table 3.3). Compared with the breast cancer reference group, respondents with a diagnosis of prostate cancer had lower odds (0.2) of having a likely presence of psychological distress.
Table 3.1: Multiple logistic regression analysis of demographic and disease characteristics of those with a HADS classified likely presence of anxiety

<table>
<thead>
<tr>
<th>Likely presence of anxiety</th>
<th>Unadjusted OR</th>
<th>Likelihood ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (column %)</td>
<td>(95% CI)</td>
<td>Chi² (df), p</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>26 (16%)</td>
<td>1</td>
</tr>
<tr>
<td>Site 2</td>
<td>19 (15%)</td>
<td>0.9 (0.5-1.8)</td>
</tr>
<tr>
<td>Site 3</td>
<td>12 (16%)</td>
<td>1.0 (0.5-2.2)</td>
</tr>
<tr>
<td>Site 4</td>
<td>9 (11%)</td>
<td>0.6 (0.3-1.4)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49</td>
<td>20 (22%)</td>
<td>1</td>
</tr>
<tr>
<td>50-59</td>
<td>21 (21%)</td>
<td>1.0 (0.5-1.9)</td>
</tr>
<tr>
<td>60-69</td>
<td>16 (11%)</td>
<td>0.4 (0.2-0.9)</td>
</tr>
<tr>
<td>70+</td>
<td>9 (8.0%)</td>
<td>0.3 (0.1-0.7)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>21 (9.0%)</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>45 (20%)</td>
<td>2.6 (1.5-4.5)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer</td>
<td>23 (17%)</td>
<td>1</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>2 (2.9%)</td>
<td>0.1 (0.02-0.4)</td>
</tr>
<tr>
<td>Other common cancer a</td>
<td>23 (17%)</td>
<td>0.9 (0.5-1.8)</td>
</tr>
<tr>
<td>Other or unknown cancer</td>
<td>18 (21%)</td>
<td>1.2 (0.6-2.5)</td>
</tr>
</tbody>
</table>

Note. Observations within each variable may not add to the total due to missing values.

a Includes brain cancer, colorectal cancer, head and neck cancer, lung cancer and non-Hodgkin’s lymphoma

b Assessed using the Hospital Anxiety and Depression Scale (HADS) anxiety subscale threshold score of ≥11
Table 3.2: Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of depression

<table>
<thead>
<tr>
<th>Hospital Site</th>
<th>Likely presence of depression b n (column %)</th>
<th>Unadjusted OR (95% CI)</th>
<th>Likelihood ratio Chi² (df), p Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>12 (7.2%)</td>
<td>1</td>
<td>5.2 (3), p = 0.2</td>
</tr>
<tr>
<td>Site 2</td>
<td>6 (4.6%)</td>
<td>0.6 (0.2-1.7)</td>
<td>0.8 (0.3-2.2)</td>
</tr>
<tr>
<td>Site 3</td>
<td>7 (9.5%)</td>
<td>1.3 (0.5-3.6)</td>
<td>1.3 (0.5-3.5)</td>
</tr>
<tr>
<td>Site 4</td>
<td>1 (1.2%)</td>
<td>0.2 (0.02-1.2)</td>
<td>0.2 (0.02-1.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age group</th>
<th>Likely presence of depression b n (column %)</th>
<th>Unadjusted OR (95% CI)</th>
<th>Likelihood ratio Chi² (df), p Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-49</td>
<td>6 (6.5%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>9 (9.1%)</td>
<td>1.4 (0.5-4.2)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>9 (6%)</td>
<td>0.9 (0.3-2.7)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>2 (1.8%)</td>
<td>0.3 (0.05-1.3)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>Likely presence of depression b n (column %)</th>
<th>Unadjusted OR (95% CI)</th>
<th>Likelihood ratio Chi² (df), p Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>4 (3.1%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>1 (1.0%)</td>
<td>0.3 (0.04-2.9)</td>
<td>0.3 (0.04-3.1)</td>
</tr>
<tr>
<td>Other common cancer a</td>
<td>14 (10%)</td>
<td>3.6 (1.2-11.3)</td>
<td>3.4 (1.1-10.8)</td>
</tr>
<tr>
<td>Other or unknown cancer</td>
<td>7 (8.1%)</td>
<td>2.8 (0.8-9.9)</td>
<td>2.5 (0.9-9.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Palliative treatment aim</th>
<th>Likely presence of depression b n (column %)</th>
<th>Unadjusted OR (95% CI)</th>
<th>Likelihood ratio Chi² (df), p Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>19 (5.0%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (10%)</td>
<td>2.1 (0.8-5.6)</td>
<td></td>
</tr>
</tbody>
</table>

Note. Observations within each variable may not add to the total due to missing values

a Includes brain cancer, colorectal cancer, head and neck cancer, lung cancer and non-Hodgkin lymphoma

b Assessed using the Hospital Anxiety and Depression Scale (HADS) depression subscale threshold score of ≥11
**Table 3.3**: Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of psychological distress

<table>
<thead>
<tr>
<th></th>
<th>Likely presence of psychological distress&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Unadjusted OR (95% CI)</th>
<th>Likelihood ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (column %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
<td>(95% CI)</td>
</tr>
<tr>
<td>Site 1</td>
<td>42 (25%)</td>
<td>1</td>
<td>1 (3), &lt;i&gt;p = 0.8&lt;/i&gt;</td>
</tr>
<tr>
<td>Site 2</td>
<td>24 (18%)</td>
<td>0.7 (0.4-1.2)</td>
<td>0.8 (0.4-1.4)</td>
</tr>
<tr>
<td>Site 3</td>
<td>19 (26%)</td>
<td>1.0 (0.5-1.9)</td>
<td>1.0 (0.5-2.0)</td>
</tr>
<tr>
<td>Site 4</td>
<td>17 (20%)</td>
<td>0.7 (0.4-1.4)</td>
<td>0.9 (0.5-1.8)</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49</td>
<td>24 (26%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>32 (32%)</td>
<td>1.4 (0.7-2.5)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>28 (19%)</td>
<td>0.7 (0.3-1.2)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>18 (16%)</td>
<td>0.5 (0.3-1.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45 (19%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57 (26%)</td>
<td>1.5 (0.9-2.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td>29 (3), &lt;i&gt;p &lt; 0.001&lt;/i&gt;*</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>30 (23%)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>5 (5.0%)</td>
<td>0.2 (0.07-0.5)</td>
<td>0.2 (0.06-0.5)</td>
</tr>
<tr>
<td>Other common cancer&lt;sup&gt;a&lt;/sup&gt;</td>
<td>41 (30%)</td>
<td>1.4 (0.8-2.5)</td>
<td>1.4 (0.8-2.4)</td>
</tr>
<tr>
<td>Other or unknown cancer</td>
<td>26 (30%)</td>
<td>1.5 (0.8-2.7)</td>
<td>1.4 (0.7-2.6)</td>
</tr>
</tbody>
</table>

*Note*. Observations within each variable may not add to the total due to missing values.

<sup>a</sup> Includes brain cancer, colorectal cancer, head and neck cancer, lung cancer, and non-Hodgkin’s lymphoma.

<sup>b</sup> Assessed using the Hospital Anxiety and Depression Scale (HADS) total threshold score of ≥15.
Survey acceptability

Of the 159 respondents, the majority agreed that the touchscreen computer survey that they had just completed was easy to use (99%; 95% CI 96-100%), allowed enough privacy (99%; 95% CI 97-100%), had questions that were easy to understand (96%; 95% CI 92-99%), instructions that were easy to follow (99%; 95% CI 96-100%), and that they felt comfortable answering the questions (99%; 95% CI 97-100%). Overall, 111 participants (70%; 95% CI 62-77%) indicated that they would be willing to complete a touchscreen computer survey while waiting for the RT appointment on more than one visit to the radiotherapy treatment centre. Thirteen percent (95% CI 7.9-19%) said they would be willing to do this on less than half the visits, 15% (95% CI 9.9-22%) on half of the visits, 28% (95% CI 21-36%) on most of the visits and 14% (95% CI 8.9-20%) on every visit.

3.5 Discussion

Proportion of outpatients with a likely presence of anxiety, depression and distress

Using HADS subscale threshold score of 11, a likely presence of anxiety was observed in 15% of participants and depression in 5.6%. Previous studies conducted in the UK using the HADS have reported anxiety in between 9% and 19% and depression in between 5% and 9% of radiotherapy patients [15, 35]. Similarly, Pascoe et al [12] found that in a sample of 504 Australian oncology outpatients (of whom 41% were receiving radiotherapy), approximately 12% were likely cases of anxiety and 7% were likely cases of depression.

Debate remains about whether it is most appropriate to use the HADS total score or the subscale scores, which allow bi-dimensional assessment of anxiety and depression [36, 37]. In the present study, using a HADS-T threshold of ≥15, close to one quarter of respondents were identified with a likely presence of psychological distress. This is consistent with research applying the same total threshold score recommended by
Ibbotson et al [25]. Strong et al [14] and Sharpe et al [38] conducted studies in cancer patient populations in the UK and identified a likely presence of distress using the HADS total score in 22 and 23% of patients, respectively.

Factors associated with a likely presence of anxiety, depression and distress

Respondents aged 70 or more had marginally significantly lower odds of experiencing a likely presence of anxiety according to the HADS than the younger respondent group aged 18-49 years. It has been previously reported that younger cancer patients are likely to experience more severe distress [39]. However, Aass et al [18] identified lower levels of anxiety in Norwegian cancer patients under 30 and over 70, suggesting anxiety was greater in middle-aged cancer patients. Pascoe et al [12] did not find any association between age group and anxiety or depression using a binary categorisation of age group (<65 and ≥65). It seems likely that the categorical groupings of age across these studies may relate to the discrepancies between these findings. In the current study, the youngest age group (and reference category) was from 18 to 49 years. It is possible that lower anxiety in respondents aged less than 30 was not detected because of this categorisation; however, due to the low numbers of respondents aged less than 30 in the current study, this relationship was not examined further.

In the current study, no association was found between sex and a likely presence of anxiety. In contrast, previous studies have reported that female sex is associated with higher anxiety [19, 30]. However, it was found that compared to breast cancer patients, patients with a prostate cancer diagnosis had lower odds of having a likely presence of anxiety and/or overall psychological distress. A study of 4,496 cancer patients with common cancer types (lung, brain, Hodgkin’s lymphoma, pancreas, lymphoma, liver, head and neck, adenocarcinoma, breast, leukaemia, melanoma, colon, prostate and gynaecological) suggested that psychological distress prevalence varied by cancer
type, with a trend towards prostate cancer patients having lower mean anxiety and
depression scores than breast cancer patients [13]. It is possible that this finding by
cancer type may be a surrogate for sex; however, more investigation of this is
warranted.

The odds of a likely presence of depression were 3.3 times higher in respondents
diagnosed with other common cancer types (including brain, colorectal, head and neck,
lung, melanoma and non-Hodgkin’s lymphoma) compared to respondents diagnosed
with breast cancer. This is consistent with past findings indicating that patients
diagnosed with some common and less common cancer types (e.g. lung cancer, brain
cancer and pancreatic cancer) report high levels of distress [3, 13, 40].

**Acceptability of psychological screening within radiotherapy treatment centres**

Radiotherapy treatment centre-based assessment of psychological distress appears to
be both feasible and highly acceptable to patients. Consent rates to the current study
were high and a large proportion of participants also indicated that they would be
willing to complete additional touchscreen computer surveys in the same setting on
future occasions.

**Limitations**

The HADS appears to be a sensitive instrument for screening purposes; however, the
selection of threshold scores should be carefully considered [28]. The HADS is likely to
provide a good indication of the likely presence of anxiety, depression and
psychological distress among cancer outpatients, particularly when used in similar
settings to previous studies applying the same threshold scores.

Selection of patients undergoing outpatient radiotherapy treatment is likely to have
limited the current sample to well-functioning patients. There are a number of other
disease variables which have been linked to mood outcomes in the past, including
variables relating to current physical status [9]. These factors were not assessed is the
current study, as any large variation in physical status is likely to have been screened out of the study by the selection of outpatients only.

Although a priori sample size and power calculations were undertaken, because the prevalence of depression was lower than anticipated, the study is likely to be underpowered to detect relationships between explanatory variables and this outcome. At least 800 participants would have been needed to detect differences of 20% in characteristics between groups with 5% significance level and 80% power.

**Implications**

The likely presence of anxiety and depression was found to be slightly higher in this patient population compared to normative data from a non-clinical UK population using the same HADS threshold scores, where 13% were identified with a likely presence of anxiety and 3.6% with a likely presence of depression [41]. Since RT patients attend daily treatments and weekly treatment reviews, a window of opportunity exists for clinicians to intervene with patients in this setting [11]. Assessment of psychological distress in a radiotherapy treatment centre setting using touchscreen computers appears to be both feasible and acceptable to cancer patients.

The odds of a likely presence of anxiety, depression and overall psychological distress were found to differ by cancer type. This might reflect differences in prognosis, treatments or potentially in models of care. For instance, some cancer types are associated with worse side effects from radiotherapy treatment [42]. It has also been suggested that elevated levels of proinflammatory cytokines in some cancer types may be linked to higher rates of depression [43]. Alternatively, although tumour-specific nurse specialists or care coordinators are now available within institutions for more common cancer types, not all cancer types are routinely linked into a service such as this [44]. A limitation of this finding is that socio-demographic and medical predictor variables assessed in this study were all collected via patient self-report. Although self-
reported data have been criticised for lacking accuracy as a result of recall biases [45],
the accuracy of self-reported variables such as cancer type and time since diagnosis
have been shown to be comparable with cancer registry data [33]. Future research
should investigate in more detail these differences between cancer types.

Conclusions
This study provides information on the likely presence of anxiety and depression in a
heterogeneous sample of cancer patients. The current findings partially support
previous research suggesting an association between younger cancer patients and
elevated levels of anxiety. Additionally, these findings also raise the question of how
cancer type may influence a likely presence of anxiety, depression and psychological
distress. Assessment of psychological distress in RT treatment centres appears to be
acceptable to patients. RT settings hold promise for system-based identification and
referral of oncology outpatients potentially affected by anxiety, depression and
psychological distress.

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touchscreen computer resources and patient recruitment costs were covered by a 2009
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Conflict of interest

No authors have reported financial relationships with research sponsoring organizations. Ms Lisa Mackenzie, the corresponding author, had and has full control of the primary data. The authors agree to allow *Supportive Care in Cancer* to review the data, if requested.

Disclosures

None.
3.6 References


PAPER FOUR

Agreement between HADS classifications and single-item screening questions for anxiety and depression: A cross-sectional survey of cancer patients

In Paper Three, the reported prevalence of anxiety, depression and overall distress, as measured by the Hospital Anxiety and Depression Scale (HADS), was 15%, 5.7% and 22% respectively. The touch screen computer psychosocial survey was found to be acceptable to respondents. In busy radiation oncology treatment centres, system-based identification and referral of patients who may be experiencing anxiety, depression and psychological distress may be improved by the availability of screening tools that are even briefer than standardised tools such as the HADS [1-3]. An example of this is ultra-short screening, which can involve asking patients questions such as, “Are you depressed?” [4] and “Are you anxious?” [5]. However, patients’ perceptions regarding whether they are anxious or depressed may be incompatible with the results of standardised screening assessments such as the HADS. Some patients classified as anxious or depressed using standardised assessment tools do not accept referrals or seek treatments recommended to them, because they either do not consider themselves to be distressed, or prefer self-management or other strategies for coping with distress [6-8]. Conversely, some patients who perceive that they are experiencing anxiety or depression but who are classified with sub-threshold anxiety or depression on standardised measures may not be offered access to psychosocial support services [7, 9, 10]. Paper Four reports agreement between patient-perceived and HADS-classified levels of anxiety and depression [5, 11] among radiation oncology outpatients and examines which of these provides a better model of a patient’s preference to be offered support. The proportion of patients who, if they were experiencing anxiety and
depression, would accept (or were currently using) a range of psychosocial support service is also reported.

This paper was published in *Annals of Oncology* (see Appendix 4.1).

References


Agreement between HADS classifications and single-item screening questions for anxiety and depression: A cross-sectional survey of cancer patients

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3. Centre for Clinical Epidemiology and Biostatistics, School of Medicine and Public Health, Faculty of Health, University of Newcastle, Callaghan, New South Wales 2308, Australia
4.1 Abstract

Background

We assessed agreement between reported anxiety and depression levels of cancer patients using (i) single self-report items and (ii) the Hospital Anxiety and Depression Scale (HADS). We also explored whether anxiety and depression assessment by (i) single self-report items or (ii) the HADS was most strongly associated with a preference to be offered professional assistance. The proportion of patients indicating that they would accept (or were currently using) professional support if they were experiencing anxiety or depression was also examined.

Patients and methods

A consecutive sample of cancer patients undergoing radiotherapy at four metropolitan public hospitals in Australia completed a touchscreen computer survey. A consecutive subsample of patients attending three of these treatment centres answered additional questions about psychological support preferences.

Results

Of 304 respondents, 54% (95% Confidence Interval [CI] 48% to 60%) perceived that they were currently experiencing mild to severe anxiety and depression. 22% (95% CI 18% to 27%) indicated a preference to be offered professional help. There was moderate agreement between the HADS and single-item responses for categorisation of anxiety and depression. Patient-perceived mild to severe anxiety and depression levels appeared to be the best measure for identifying those with a preference to be offered professional assistance. Of a subsample of 193 respondents, 89% (95% CI 84% to 93%) indicated that if they were experiencing anxiety or depression, they would accept (or were currently using) professional support.

Conclusions
Single-item screening in a cancer care setting may not adequately capture clinical anxiety and depression. However, single items assessing patients’ perceived levels of anxiety and depression are useful indicators of whether patients want to be offered, and are likely to accept, psychosocial care.

**Keywords:** anxiety, depression, HADS, oncology, questionnaire, single-item question

**Key message:**
Compared with HADS classifications, cancer patients’ perceived levels of anxiety and depression were more strongly associated with a preference to be offered professional support. Responding to patients’ perceived anxiety, depression and preferences for professional help may be an appropriate patient-centred approach. However, this approach would need to consider priorities for limited psychosocial resources.
4.2 Introduction

Psychosocial issues are under-recognised and under-treated in cancer patients [1, 2]. Resource efficient and effective methods of detection and treatment of psychosocial distress are needed. Ultra-short measures of anxiety and depression have potential to improve timely recognition of these conditions [3, 4].

Ultra-short measures such as the Distress Thermometer (DT) require patients to provide a numerical index of perceived distress [3, 5]. Ultra-short screening questions require patients to provide a yes or no response to single questions such as “Are you depressed?” [4]. The DT and ultra-short screening questions have been found to have good ability to exclude non-cases (specificity), but a poorer ability to detect possible cases (sensitivity) [6, 7]. Increasing the number of response categories in single-item measures may help improve sensitivity [8]. We aimed to assess agreement between single-item measures asking patients to indicate their perceived level of (i) anxiety and (ii) depression, and similar categories recommended for the Hospital Anxiety and Depression Scale (HADS) [4, 8, 9]. Despite psychometric shortcomings [10, 11], the HADS is recommended for brief screening for anxiety and depression in oncology [9].

Cancer patients’ perception of their own level of anxiety and depression may impact on their uptake of psychosocial service referrals [2, 12-15]. We aimed to explore whether the HADS or patients’ perceived levels of distress provided the best indicator for identifying those with a preference to be offered professional help for anxiety and/or depression. We also describe the proportion of patients indicating that, if they were experiencing anxiety or depression, they would accept professional psychosocial support.

4.3 Method

Ethics approvals
Ethics approvals were obtained from the University of Newcastle and the New South Wales Population and Health Services Research Ethics Committees.

**Design and setting**
A cross sectional survey was conducted at four radiation oncology treatment centres attached to metropolitan public hospitals in the Australian state of New South Wales. Each participating centres had a minimum of two linear accelerators available for radiotherapy, with average treatment throughput varying between 60 and 140 patients per day.

**Participants**
Cancer patients attending radiotherapy appointments; aged 18 years or older; able to complete the survey in English; and able to give informed consent were eligible for the study.

**Procedure**
A research assistant provided potential participants with written and verbal information about the study. Completion of the touch screen computer survey was taken as informed consent.

**Measures**
The following were included in a larger survey examining perceptions of, and preferences for, patient centred cancer care [16, 17]:

*Participant demographic and medical characteristics*
Participants reported their age, gender, postcode, region of birth, who they live with, when they were first diagnosed with cancer, if they had experienced a second cancer diagnosis or recurrence, most recent primary cancer diagnosis, and perceived aim of current treatment.

*Patients’ perceptions of their psychological distress*
Participants were asked, “What level of anxiety have you been experiencing in the last week?” and “What level of depression have you been experiencing in the last week?” Response options were “No anxiety; Mild anxiety; Moderate anxiety; or Severe anxiety” and “No depression; Mild depression; Moderate depression; Severe depression” respectively.

**Psychological distress**

The HADS contains two 7-item subscales that measure depression (HADS-D) and anxiety (HADS-A) in the prior week. Scores were categorised as normal (0-7), mild (8-10), moderate (11-14), and severe (15-21) [18]. The characteristics of participants meeting HADS threshold scores are reported elsewhere [16].

**Preference to be offered professional support**

Participants were asked: “Given your current levels of anxiety and/or depression, would you like to be offered some professional help?” Those who responded “no” were asked “Why don’t you want professional support for anxiety and/or depression?”

**Willingness to accept professional help for anxiety or depression**

A subsample of consecutive patients attending the first three participating treatment centres were asked “If you were experiencing anxiety or depression; would you accept the following types of professional help?” in reference to: group counselling at the cancer centre; individual counselling at the cancer centre; treatment/counselling from my cancer doctor; group counselling outside the cancer centre; individual counselling outside the cancer centre; treatment/counselling from my GP; internet (online) support. All support types were listed on a single question screen in a matrix format, with the response options i) no, definitely not; ii) no, probably not; iii) yes, probably; and iv) yes, currently using.

**Statistical analysis**

*Agreement between HADS and patients*
Agreement between HADS categories (normal, mild, moderate and severe) [18] and self-classification of anxiety and depression (none, mild, moderate and severe) was assessed using weighted κ (bias adjusted), with bootstrapping techniques to estimate 95% confidence intervals (CIs). The Stuart-Maxwell test for marginal homogeneity was used to assess whether cancer patients tend to self-rate their anxiety or depression higher or lower than the HADS ratings.

**Indicators of a preference for being offered support**

Univariate logistic regression analyses were used to identify factors associated with a preference to be offered professional support. Variables included age category, sex, country of birth, cancer type, perceived treatment aim, anxiety and depression. Variables with a \( p \) value of \( \leq 0.2 \) were included in four separate non-nested multiple logistic regression models. Each model included one of the four different anxiety and depression terms (see S1 for description of terms a-d). Recruitment site was included as an adjustment for the sampling strategy. The backward stepwise method was used to remove variables with a \( p \) value of \( \geq 0.1 \) on the likelihood ratio test. To ensure comparability of models, any explanatory variable retained in the final model was included in all models. Odds ratios with 95% CIs are reported. The most appropriate measure for investigating the relationship with preference for professional support was assessed by i) the amount of missing data, ii) the significance of the likelihood ratio test terms in the models, iii) the Hosmer-Lemeshow goodness of fit measure and iv) the relative fit of the models using the Aikake Information Criterion (AIC).

**Willingness to accept support**

The proportion of patients with a willingness to accept professional support for anxiety and depression is reported with 95% CIs. See S1 for detail of analyses.

See S2 for sample size calculations. All analyses were conducted using Stata version 11.2 (StataCorp, Texas, USA), applying a significance level of 5%.
4.4 Results

Of 529 patients screened for inclusion in the study, 98 were excluded due to:
1. Insufficient English proficiency (n = 45);
2. Not currently receiving radiotherapy (n = 29);
3. Already having been approached about the survey (n = 6);
4. Clinic staff concern about patient burden or capacity to give informed consent (n = 3);
5. Being under the age of 18 (n = 2);
6. Not having a cancer diagnosis (n = 1) or an unspecified reason (n = 12).

Of the 431 eligible patients, 369 consented (86%), and 304 (71%) completed the survey. Non-completion was typically due to patients having insufficient time prior to their treatment appointment. Only surveys with complete data are included in the analyses. On average, respondents were 61.6 years old (SD = 13.8, minimum = 18.9, maximum = 91.4). Additional sample characteristics are in Table 4.1.

Agreement between patients’ perceptions and HADS classifications

One hundred and sixty-four participants (54%, 95% CI 48% to 60%) perceived that they were experiencing mild to severe anxiety or depression. Tables 4.2 and 4.3 provide the numbers of patients with each self-perceived and HADS level of anxiety, and depression, respectively.

Table 4.2 indicates the level of agreement between HADS anxiety classifications and patients’ self-reported levels. The observed proportion of agreement was 93%, with weighted κ of 0.5 (95% CI 0.4 to 0.6) indicating moderate agreement between patients’ perceptions and the HADS (p < 0.0001). The Stuart Maxwell test of marginal homogeneity was significant (χ² (3) = 49, p < 0.0001); patients generally reported higher levels of anxiety than was indicated by HADS-A classification levels (see Table 4.2).

Table 4.3 shows the level of agreement between HADS depression classifications and patients’ self-reported levels. The observed proportion of agreement was 95%, with weighted κ of 0.5 (95% CI: 0.4 to 0.6) indicating moderate agreement (p < 0.0001). The
Stuart Maxwell test of marginal homogeneity was significant ($\chi^2 (3) = 30, p < 0.0001$); patients generally reported higher levels of depression than what was determined from their HADS-D score (See Table 4.3).

**Patient preference to be offered professional support**

Sixty-seven participants expressed a preference to be offered professional support for their anxiety and/or depression (22%, 95% CI 18% to 27%). Of these, 51% ($n = 34$, 95% CI 38 to 63%) met HADS threshold scores for mild to severe anxiety and/or depression. Reasons for preferring not to be offered support are presented in S3. These findings suggest that self-reported anxiety and depression levels may better predict a preference to be offered professional support than HADS classifications.

Table 4.4 presents the results of the univariate analysis for all included variables, and the multivariate analysis of Models a-d (See S1). The full number of observations ($n = 304$) was available for all models. In Models a-d, patients classified with anxiety had significantly higher odds of a preference to be offered professional support for current anxiety and/or depression. In Model c patients classified with depression had significantly higher odds of a preference to be offered professional support for current anxiety and/or depression. This was not the case for Models a, b and d. The Hosmer-Lemeshow test results indicated that all models fit the data well. The relative fit of the models using the AIC indicated that Model c was marginally the strongest model, followed by Models d, a and b. Based on the specified criteria, Model c (patient-perceived mild-severe anxiety and depression) has the strongest association with a patient preference to be offered professional support for current levels of anxiety and/or depression.

**Willingness to accept professional help for anxiety and/or depression**

Of 193 respondents to these questions, 89% ($n = 172$; 95% CI: 84-93%) indicated that if they were experiencing anxiety or depression, they either would probably use or were
currently using at least one support service. S4 shows the proportions of patients willing to accept support. S5 shows the final multiple logistic regression models assessing factors associated with accepting different types of support. S6 shows the proportion of respondents who would probably accept or were currently using support, grouped by different distress assessment methods. All respondents with a preference to be offered professional support indicated they would probably accept (or were using) at least one form of professional support if they were experiencing anxiety or depression.
Table 4.1: Characteristics of the sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Overall sample (n = 304)</th>
<th>Support preferences subsample (n = 193)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Males</strong></td>
<td>158 (52)</td>
<td>99 (51)</td>
</tr>
<tr>
<td><strong>Age group (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49</td>
<td>64 (21)</td>
<td>39 (20)</td>
</tr>
<tr>
<td>50-59</td>
<td>58 (19)</td>
<td>34 (18)</td>
</tr>
<tr>
<td>60-69</td>
<td>99 (33)</td>
<td>62 (32)</td>
</tr>
<tr>
<td>70+</td>
<td>83 (27)</td>
<td>58 (30)</td>
</tr>
<tr>
<td><strong>Australian born</strong></td>
<td>202 (66)</td>
<td>132 (68)</td>
</tr>
<tr>
<td><strong>Living with:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband/wife/partner</td>
<td>187 (62)</td>
<td>119 (62)</td>
</tr>
<tr>
<td>Children/step-children</td>
<td>65 (21)</td>
<td>42 (22)</td>
</tr>
<tr>
<td>Other family</td>
<td>22 (7.2)</td>
<td>12 (6.2)</td>
</tr>
<tr>
<td>Friend/s</td>
<td>8 (2.6)</td>
<td>6 (3.1)</td>
</tr>
<tr>
<td>Unrelated flatmate/co-tenant</td>
<td>4 (1.3)</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td>Living alone</td>
<td>62 (20)</td>
<td>38 (20)</td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>77 (25)</td>
<td>53 (27)</td>
</tr>
<tr>
<td>Prostate</td>
<td>68 (22)</td>
<td>44 (23)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>31 (10)</td>
<td>17 (8.8)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>17 (5.5)</td>
<td>9 (4.7)</td>
</tr>
<tr>
<td>Lung</td>
<td>16 (5.3)</td>
<td>8 (4.1)</td>
</tr>
<tr>
<td>Brain</td>
<td>12 (3.9)</td>
<td>8 (4.1)</td>
</tr>
<tr>
<td>Non Hodgkin Lymphoma</td>
<td>11 (3.6)</td>
<td>7 (3.6)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>10 (3.3)</td>
<td>5 (2.6)</td>
</tr>
<tr>
<td>Other</td>
<td>56 (18)</td>
<td>38 (20)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (2.0)</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td><strong>Perceived palliative treatment aim</strong></td>
<td>48 (16)</td>
<td>35 (19)</td>
</tr>
<tr>
<td><strong>Second diagnosis or recurrence</strong></td>
<td>93 (32)</td>
<td>59 (32)</td>
</tr>
<tr>
<td><strong>Hospital site</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>62 (20%)</td>
<td>62 (32%)</td>
</tr>
<tr>
<td>Site 2</td>
<td>83 (27%)</td>
<td>83 (43%)</td>
</tr>
<tr>
<td>Site 3</td>
<td>75 (25%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Site 4</td>
<td>84 (28%)</td>
<td>48 (25%)</td>
</tr>
<tr>
<td>Characteristics</td>
<td>Overall sample (n = 304)</td>
<td>Support preferences subsample (n = 193)</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Median (Q1, Q3)</td>
<td>Median (Q1, Q3)</td>
</tr>
<tr>
<td>Number of outpatient clinic appointments</td>
<td>3 (2, 4)</td>
<td>3 (2, 4)</td>
</tr>
<tr>
<td>Number of radiotherapy treatment</td>
<td>8 (3, 16)</td>
<td>7 (3, 15)</td>
</tr>
<tr>
<td>Weeks since diagnosis</td>
<td>28.2 (15.9, 69.0)</td>
<td>29.2 (15.9, 74.1)</td>
</tr>
</tbody>
</table>

*Note. Due to missing values, non-mutually exclusive categories and rounding, numbers for some variables may not add to total sample size.*

**Table 4.2**: Number and percentage of patients whose HADS anxiety levels agree with their perceived anxiety levels

<table>
<thead>
<tr>
<th>Perceived level of anxiety</th>
<th>Normal anxiety</th>
<th>Mild anxiety</th>
<th>Moderate anxiety</th>
<th>Severe anxiety</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No anxiety</td>
<td>138 (90%)</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>153</td>
</tr>
<tr>
<td>Mild anxiety</td>
<td>62</td>
<td>21 (21%)</td>
<td>15</td>
<td>1</td>
<td>99</td>
</tr>
<tr>
<td>Moderate anxiety</td>
<td>16</td>
<td>10</td>
<td>18 (36%)</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Severe anxiety</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1 (50%)</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>216</td>
<td>45</td>
<td>35</td>
<td>8</td>
<td>304</td>
</tr>
</tbody>
</table>

**Table 4.3**: Number and percentage of patients whose HADS depression levels agree with their perceived depression levels

<table>
<thead>
<tr>
<th>Perceived level of depression</th>
<th>Normal depression</th>
<th>Mild depression</th>
<th>Moderate depression</th>
<th>Severe depression</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No depression</td>
<td>195 (93%)</td>
<td>13</td>
<td>1</td>
<td>0</td>
<td>209</td>
</tr>
<tr>
<td>Mild depression</td>
<td>46</td>
<td>15 (23%)</td>
<td>3</td>
<td>1</td>
<td>65</td>
</tr>
<tr>
<td>Moderate depression</td>
<td>9</td>
<td>10</td>
<td>9 (31%)</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Severe depression</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0 (0%)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>251</td>
<td>38</td>
<td>13</td>
<td>2</td>
<td>304</td>
</tr>
</tbody>
</table>
Table 4.4: Likelihood ratio (LR) univariate and multiple logistic regression results from four logistic regression models of the outcome, “current preference to be offered professional support for anxiety and/or depression” (n = 304)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Desire to be offered support</th>
<th>Univariate logistic regression</th>
<th>Multiple logistic regression</th>
<th>Multiple logistic regression</th>
<th>Multiple logistic regression</th>
<th>Multiple logistic regression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (row %)</td>
<td>LR $X^2$ (df), $p$</td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>23 (37%)</td>
<td>30.6 (3), $p&lt;0.0001^*$</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Site 2</td>
<td>28 (34%)</td>
<td>33.4 (3), $p&lt;0.0001^*$</td>
<td>0.9 (0.4-1.7)</td>
<td>0.8 (0.4-1.7)</td>
<td>0.8 (0.5-2.1)</td>
<td>0.8 (0.4-1.7)</td>
</tr>
<tr>
<td>Site 3</td>
<td>10 (13%)</td>
<td>30.4 (3), $p&lt;0.0001^*$</td>
<td>0.3 (0.1-0.6)</td>
<td>0.2 (0.1-0.5)</td>
<td>0.2 (0.1-0.6)</td>
<td>0.2 (0.1-0.5)</td>
</tr>
<tr>
<td>Site 4</td>
<td>6 (7%)</td>
<td>31.1 (3), $p&lt;0.0001^*$</td>
<td>0.1 (0.05-0.3)</td>
<td>0.1 (0.04-0.3)</td>
<td>0.1 (0.05-0.4)</td>
<td>0.1 (0.04-0.3)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td>30.6 (3), $p&lt;0.0001^*$</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>18-49</td>
<td>15 (23%)</td>
<td>0.2 (3), $p=0.9780$</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>13 (19%)</td>
<td>0.9 (0.4-2.2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>22 (33%)</td>
<td>0.9 (0.4-2.0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>17 (25%)</td>
<td>0.8 (0.4-1.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34 (22%)</td>
<td>0.1 (1), $p=0.8199$</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>33 (23%)</td>
<td></td>
<td>1.1 (0.6-1.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Desire to be offered support n (row %)</td>
<td>Univariate logistic regression</td>
<td>Multiple logistic regression Model a</td>
<td>Multiple logistic regression Model b</td>
<td>Multiple logistic regression Model c</td>
<td>Multiple logistic regression Model d</td>
</tr>
<tr>
<td>-----------</td>
<td>--------------------------------------</td>
<td>-------------------------------</td>
<td>------------------------------------</td>
<td>------------------------------------</td>
<td>------------------------------------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td></td>
<td>LR $X^2$(df), $p$</td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>Australian-born</td>
<td>Yes</td>
<td>39 (19%)</td>
<td>2.6 (1), $p=0.1100^c$</td>
<td>1.4 (1), $p=0.2307^d$</td>
<td>2.0 (1), $p=0.1554^d$</td>
<td>1.0 (1), $p=0.3211^d$</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>28 (27%)</td>
<td>1.6 (0.9-2.8)</td>
<td>1.5 (0.8-2.8)</td>
<td>1.6 (0.8-2.9)</td>
<td>1.4 (0.7-2.7)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td>Yes</td>
<td>48 (20%)</td>
<td>2.1 (1), $p=0.1463^c$</td>
<td>1.6 (1), $p=0.2126^d$</td>
<td>1.6 (1), $p=0.2084^d$</td>
<td>1.2 (1), $p=0.2733^d$</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>14 (29%)</td>
<td>1.7 (0.8-3.4)</td>
<td>1.6 (0.8-3.5)</td>
<td>1.6 (0.8-3.5)</td>
<td>1.6 (0.7-3.4)</td>
</tr>
<tr>
<td>Cancer type</td>
<td>Breast</td>
<td>19 (25%)</td>
<td>1.9 (2), $p=0.3860$</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Prostate</td>
<td>11 (16%)</td>
<td>0.6 (0.3-1.3)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Other $^a$</td>
<td>37 (23%)</td>
<td>0.9 (0.5-1.7)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>HADS mild-severe anxiety $^b$</td>
<td>Yes</td>
<td>39 (18%)</td>
<td>6.6 (1), $p=0.0104^c$</td>
<td>8.4 (1), $p=0.0038^e$</td>
<td>2.1 (1.2-3.7)</td>
<td>2.7 (1.4-5.4)</td>
</tr>
<tr>
<td>Variables</td>
<td>Desire to be offered support</td>
<td>Univariate logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
</tr>
<tr>
<td>---------------------------------</td>
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<td>------------------------------</td>
<td>------------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td></td>
<td>n (row %)</td>
<td>LR $\chi^2$(df), $p$</td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>HADS mild-severe depression $^b$</td>
<td></td>
<td>2.3 (1), $p=0.1262^c$</td>
<td>0.01 (1), $p=0.9214$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>51 (20%)</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16 (30%)</td>
<td>1.7 (0.9-3.3)</td>
<td>1.0 (0.4-2.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS moderate-severe anxiety $^b$</td>
<td></td>
<td>8.0 (1), $p=0.0048^c$</td>
<td>6.8 (1), $p=0.0089^e$</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>50 (19%)</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17 (40%)</td>
<td>2.8 (1.4-5.5)</td>
<td>2.9 (1.3-6.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS moderate-severe depression $^b$</td>
<td></td>
<td>1.1 (1), $p=0.3020^c$</td>
<td>0.00 (1), $p=0.9512$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>62 (21%)</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (33%)</td>
<td>1.8 (0.6-5.6)</td>
<td>1 (0.3-3.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived mild-severe anxiety</td>
<td></td>
<td>17.0 (1), $p&lt;0.0001^c$</td>
<td>5.4 (1), $p=0.0199^e$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>19 (12%)</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48 (32%)</td>
<td>3.3 (1.8-5.9)</td>
<td></td>
<td>2.3 (1.1-4.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Desire to be offered support</td>
<td>Univariate logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
</tr>
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<td>-----------------------------------</td>
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<td>-----------------------------</td>
<td>-----------------------------</td>
<td>-----------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td></td>
<td>n (row %)</td>
<td>LR $X^2$(df), $p$</td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>Perceived mild-severe depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>32 (15%)</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>35 (37%)</td>
<td>3.2 (1.8-5.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived moderate-severe anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>44 (17%)</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>23 (44%)</td>
<td>3.7 (2.0-7.1)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Perceived moderate-severe depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>51 (19%)</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16 (53%)</td>
<td>5.0 (2.3-10.9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hosmer-Lemeshow goodness of fit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hosmer–Lemeshow $\chi^2$ (7) = 9.7, $p = 0.2092$</td>
<td>Hosmer–Lemeshow $\chi^2$ (4) = 3.0, $p = 0.5557$</td>
<td>Hosmer–Lemeshow $\chi^2$ (8) = 9.4, $p = 0.3134$</td>
<td>Hosmer–Lemeshow $\chi^2$ (4) = 2.1, $p = 0.7119$</td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Univariate logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td>Multiple logistic regression</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>------------------------------</td>
<td>----------------------------</td>
<td>----------------------------</td>
<td>----------------------------</td>
<td>----------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Model a</td>
<td>Model b</td>
<td>Model c</td>
<td>Model d</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>LR $X^2$(df), $p$</td>
<td>LR $X^2$(df), $p$</td>
<td>LR $X^2$(df), $p$</td>
<td>LR $X^2$(df), $p$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (row %)</td>
<td>Unadjusted Adjusted OR</td>
<td>Adjusted OR</td>
<td>Adjusted OR</td>
<td>Adjusted OR</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>OR (95% CI)</td>
<td>(95% CI)</td>
<td>(95% CI)</td>
<td>(95% CI)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Aikake Information

| Criterion | AIC (df = 6) = 292 | AIC (df = 6) = 294 | AIC (df = 6) = 279 | AIC (df = 6) = 281 |

Note. Observations within each variable may not add to the total due to missing values

a Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types

b Assessed using the Hospital Anxiety and Depression Scale (HADS)

c Included in the initial multiple logistic regression model

d Eliminated during backwards stepwise multiple logistic regression analysis

e Significant

Model a: HADS mild-severe anxiety and/or depression
Model b: HADS moderate-severe anxiety and/or depression
Model c: Patient perceived mild-severe anxiety and/or depression
Model d: Patient perceived moderate-severe anxiety and/or depression
4.5 Discussion

Patients’ perceived levels of both anxiety and depression agreed moderately well with the levels outlined by the HADS developers. However, there were some discrepancies, with patients generally reporting higher levels relative to HADS. Screening tools either over- or under-detect likely cases depending on the threshold scores applied [10]. In this study, using ultra-short items, 50% of radiotherapy patients perceived that they were currently experiencing mild to severe levels of anxiety, and 31% mild to severe depression. Other research has reported the proportion of cancer patients perceiving they were experiencing anxiety was 58% [4], whilst depression was between 6% [8] and 37% [4]. Responses to ultra-short assessments of anxiety and depression reflect respondents’ understanding of the terms [19]. This may differ from the definitions used by the HADS. Additionally, a patient rating of “none” was compared with a HADS rating of “normal” for both anxiety and depression. The HADS categorisations of “normal anxiety” and “normal depression” do include some level of anxiety and depression, and this potential discrepancy could in part explain why some respondents rated themselves as having mild anxiety or depression, but scored in the normal category on HADS.

Similar to other studies [20, 21], we found that 22% of patients expressed a preference to be offered professional support. This preference was more strongly associated with a patient perception of mild to severe anxiety and depression (Model c) than with HADS classifications. All respondents with a preference for professional support indicated that they were currently using or would accept one or more types of professional support (S6). Patients’ perceived level or severity of anxiety and depression is likely to be an important factor in determining referral uptake.
The findings from this study pose two dilemmas for psychosocial service delivery in oncology settings: How can we ensure that those experiencing clinical levels of anxiety and depression are provided with appropriate services; and what sorts of services should be delivered to those with perceived anxiety or depression which does not reach “threshold” levels according to the HADS?

If psychosocial resources are limited, there may be a need to prioritise specialised services so that they reach those with clinically significant levels of anxiety and depression. Respondents indicated that individual support methods were considered to be more acceptable than group and online support, and support provided at the cancer centre was more acceptable than support provided external to the cancer centre (S4). Lower intensity and cost self-help strategies have been found beneficial in reducing the symptom burden in individuals with “sub-threshold” depression [22], and may be appropriate for those reporting self-perceived, but not clinically significant, anxiety and depression [23]. This approach has been recommended in stepped-care models of psychosocial care [15]. As older adults had lower odds of endorsing group and online strategies (S5), these potentially cost-effective interventions may be better suited to younger cancer patients.

For those who are identified as at-risk by the HADS but who do not self-report elevated anxiety or depression, it is important to determine whether the symptoms identified by the HADS are due to other causes. If these symptoms interfere with the patients’ functioning, then the potential benefits of seeking evidence-based treatments should be discussed [3].

These findings may be a cause to reconsider how screening can be best used to provide patient-centred cancer care [12, 20, 24]. Combining ultra-short screening with an assessment of preference to be offered psychological support may allow the detection of patients who may benefit from some form of psychosocial intervention.
However, screening instruments and clinical judgement remain crucial for identifying potentially vulnerable patients who may not have insight into the severity of their emotional distress. The implications of considering patients’ perceived distress and preferences for support, rather than relying solely on screening and clinical diagnosis, should be explored. Future research could assess links between patients’ preferences for psychological support and outcomes such as uptake and effectiveness of support services.

Acknowledgements

We would like to thank Mr Sundresan Naicker, Mrs Jay House, Miss Kelauren Barry and Dr Ryan Courtney for their assistance with data collection. We would also like to express our very great appreciation to all of the staff and patients in the participating radiation oncology departments.

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Disclosure

The authors have declared no conflicts of interest.
4.6 References

1. Bultz BD, Johansen C. Screening for distress, the 6th vital sign: where are we, and where are we going? *Psychooncology* 2011; 20: 569-571.


S1: Supplementary statistical analysis

The anxiety and depression terms included in logic regression models were as follows:
a) HADS classified mild-severe anxiety and/or depression; b) HADS classified moderate-severe anxiety and/or depression, c) perceived mild-severe anxiety and/or depression, or d) perceived moderate-severe anxiety and/or depression.

The number and proportion of respondents with a preference not to be offered professional support for anxiety and/or depression, endorsing each reason for this (single forced choice response options) is reported with 95% CIs for groups with and without a likely presence of anxiety and/or depression.

To explore the characteristics of patients indicating that if they were experiencing anxiety or depression, they would accept (or were currently using) specific types of professional support, for each of the psychological support options assessed, respondents were dichotomised on the basis of endorsement of being: a) willing to accept (patients who selected “Yes, probably” or “Yes, currently using” ) or b) not willing to accept (patients who selected “No, definitely not” or “No, probably not”) that support). Univariate logistic regression analyses were used to investigate the relationship between explanatory variables (including age [18-49, 50-59, 60-69, 70 plus], sex [male, female], cancer diagnosis [breast, prostate, other/don’t know], living with a partner [no, yes], HADS classified likely anxiety [no, yes], and HADS classified likely depression [no, yes]) and patient endorsement of a willingness to accept help. Variables with a $p$ value of 0.2 or less were then included in a multiple logistic regression model. The backwards stepwise method was then used to remove all variables with a $p$ value of 0.1 or more on the likelihood ratio test, with treatment centre included in all multiple regression models. Odds ratios with 95% confidence intervals
are reported for the final multiple regression models. The fit of the final models was assessed using the Hosmer-Lemeshow goodness of fit test.
S2: Supplementary sample size calculations

A sample of 300 patients would allow estimation of prevalence with 95% CIs within ±5% of the point estimate, weighted κ with 95% CIs within ±0.1% (assuming κ of 0.5 or more) and detection of differences in characteristics of 20% for binary explanatory variables (between patients who did and did not indicate a preference), with 5% significance level and 80% power. Based on 25-75% of respondents being willing to accept each type of professional support, a sample size of 200 would allow prevalence estimates with 95% CIs within ±7% of the point estimate. Based on 20-80% of patients being willing to accept each type of support, a sample size of 200 was sufficient to detect differences of approximately in 25% in characteristics between those indicating that they probably would and would not accept professional help, with 80% power at 5% significance level.
S3: Number and proportion of respondents who did not want an offer of professional support for current levels of anxiety/depression endorsing different reasons for this (Normal distress vs Mild to severe distress) (n = 237)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Normal distress</th>
<th>Mild to severe distress</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HADS-D &lt;8 and HADS-A &lt;8</td>
<td>HADS-D ≥8 or HADS-A ≥8</td>
</tr>
<tr>
<td></td>
<td>(n = 164)</td>
<td>(n = 73)</td>
</tr>
<tr>
<td></td>
<td>n (%) 95% CI</td>
<td>n (%) 95% CI</td>
</tr>
<tr>
<td>Not experiencing much anxiety/depression</td>
<td>119 (73%; 65-79%)</td>
<td>25 (34%; 24-46%)</td>
</tr>
<tr>
<td>Anxiety/depression is normal for someone in my situation</td>
<td>9 (5.5%; 2.5-10.1%)</td>
<td>25 (34%; 24-46%)</td>
</tr>
<tr>
<td>My anxiety/depression is not much higher than usual</td>
<td>12 (7.3%; 3.8-12%)</td>
<td>8 (11%; 4.9-20%)</td>
</tr>
<tr>
<td>Don’t think professional assistance would help</td>
<td>10 (6.1%; 3.0-11%)</td>
<td>5 (6.9%, 2.3-15%)</td>
</tr>
<tr>
<td>My anxiety/depression will reduce once this phase of treatment is</td>
<td>14 (8.5%; 4.7-14%)</td>
<td>10 (14%, 6.8-24%)</td>
</tr>
</tbody>
</table>
S4: Self-reported willingness to accept different types of professional support if experiencing anxiety or depression (n = 193)

<table>
<thead>
<tr>
<th>Type of professional assistance</th>
<th>No, definitely not</th>
<th>No, probably not</th>
<th>Yes, probably</th>
<th>Yes, currently using</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group counselling at the cancer centre</td>
<td>46 (24%)</td>
<td>72 (37%)</td>
<td>69 (36%)</td>
<td>6 (3.1%)</td>
</tr>
<tr>
<td>Individual counselling at the cancer centre</td>
<td>28 (15%)</td>
<td>33 (17%)</td>
<td>116 (60%)</td>
<td>16 (8.3%)</td>
</tr>
<tr>
<td>Treatment/ counselling from my cancer doctor</td>
<td>15 (7.8%)</td>
<td>21 (1%)</td>
<td>127 (66%)</td>
<td>30 (16%)</td>
</tr>
<tr>
<td>Group counselling outside the cancer centre</td>
<td>51 (26%)</td>
<td>81 (42%)</td>
<td>59 (31%)</td>
<td>2 (1.0%)</td>
</tr>
<tr>
<td>Individual counselling outside the cancer centre</td>
<td>38 (20%)</td>
<td>53 (27%)</td>
<td>94 (49%)</td>
<td>8 (4.1%)</td>
</tr>
<tr>
<td>Treatment/ counselling from my GP</td>
<td>25 (13%)</td>
<td>31 (16%)</td>
<td>117 (61%)</td>
<td>20 (10%)</td>
</tr>
<tr>
<td>Online/internet support</td>
<td>96 (50%)</td>
<td>48 (25%)</td>
<td>43 (22%)</td>
<td>6 (3.1%)</td>
</tr>
</tbody>
</table>

(95% CI)
S5: Univariate and multiple logistic regression analysis of characteristics associated with preferences for professional support \((n = 193)\)

<table>
<thead>
<tr>
<th>Type of support</th>
<th>Patients indicating they would accept or currently were accepting support (n, % [95% CI])</th>
<th>Characteristic</th>
<th>Patient in each category indicating they would accept or currently were accepting support (n(%))</th>
<th>Univariate analysis (LR\ Chi^2, p)</th>
<th>Final multiple logistic regression model (Hosmer Lemeshow p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group counselling at the cancer centre</td>
<td>75, 39% [32-46%]</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Hospital</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>17 (27%)</td>
<td></td>
<td></td>
<td>(\chi^2(2) = 5.2, p = 0.0749^c)</td>
<td></td>
</tr>
<tr>
<td>Site 2</td>
<td>37 (45%)</td>
<td></td>
<td></td>
<td>1(\chi^2(2) = 5.3, p = 0.0692)</td>
<td>1(p = 0.9986)</td>
</tr>
<tr>
<td>Site 4</td>
<td>21 (44%)</td>
<td></td>
<td></td>
<td>1(\chi^2(3) = 11.3, p = 0.0102^c)</td>
<td>1(\chi^2(3) = 11.5, p = 0.0095^*)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>18-49 years</td>
<td>19 (49%)</td>
<td></td>
<td></td>
<td>(\chi^2(3) = 11.3, p = 0.0102^c)</td>
<td>1(\chi^2(3) = 11.5, p = 0.0095^*)</td>
</tr>
<tr>
<td>50-59 years</td>
<td>19 (56%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69 years</td>
<td>23 (37%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 years plus</td>
<td>14 (24%)</td>
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</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>36 (36%)</td>
<td></td>
<td></td>
<td>(\chi^2(1) = 0.5, p = 0.4652)</td>
<td>1(\chi^2(1) = 0.5, p = 0.4652)</td>
</tr>
<tr>
<td>Female</td>
<td>39 (41%)</td>
<td></td>
<td></td>
<td>1(\chi(1) = 0.7-2.2)</td>
<td></td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>23 (43%)</td>
<td></td>
<td></td>
<td>(\chi^2(2) = 1.0, p = 0.6019)</td>
<td>1(\chi^2(2) = 1.0, p = 0.6019)</td>
</tr>
<tr>
<td>Prostate</td>
<td>18 (41%)</td>
<td></td>
<td></td>
<td>1(\chi^2(2) = 1.0, p = 0.6019)</td>
<td>1(\chi^2(2) = 1.0, p = 0.6019)</td>
</tr>
<tr>
<td>Other/don’t know (^a)</td>
<td>34 (35%)</td>
<td></td>
<td></td>
<td>1(\chi^2(2) = 1.0, p = 0.6019)</td>
<td>1(\chi^2(2) = 1.0, p = 0.6019)</td>
</tr>
<tr>
<td>Living with a partner</td>
<td></td>
<td></td>
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<tr>
<td>No</td>
<td>25 (34%)</td>
<td></td>
<td></td>
<td>(\chi^2(1) = 1.3, p = 0.2521)</td>
<td>1(\chi^2(1) = 1.3, p = 0.2521)</td>
</tr>
<tr>
<td>Yes</td>
<td>50 (42%)</td>
<td></td>
<td></td>
<td>1(\chi^2(1) = 1.3, p = 0.2521)</td>
<td>1(\chi^2(1) = 1.3, p = 0.2521)</td>
</tr>
<tr>
<td>Anxiety (^b)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>62 (37%)</td>
<td></td>
<td></td>
<td>(\chi^2(1) = 1.5, p = 0.2152)</td>
<td>1(\chi^2(1) = 1.5, p = 0.2152)</td>
</tr>
<tr>
<td>Yes</td>
<td>13 (50%)</td>
<td></td>
<td></td>
<td>1(\chi^2(1) = 1.5, p = 0.2152)</td>
<td>1(\chi^2(1) = 1.5, p = 0.2152)</td>
</tr>
<tr>
<td>Depression (^b)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>72 (39%)</td>
<td></td>
<td></td>
<td>(\chi^2(1) = 0.1, p = 0.8260)</td>
<td>1(\chi^2(1) = 0.1, p = 0.8260)</td>
</tr>
<tr>
<td>Yes</td>
<td>3 (43%)</td>
<td></td>
<td></td>
<td>1(\chi^2(1) = 0.1, p = 0.8260)</td>
<td>1(\chi^2(1) = 0.1, p = 0.8260)</td>
</tr>
<tr>
<td>Type of support</td>
<td>Patients indicating they would accept or currently were accepting support n, % [95% CI]</td>
<td>Characteristic</td>
<td>Patient in each category indicating they would accept or currently were accepting support n (%)</td>
<td>Univariate analysis</td>
<td>Final multiple logistic regression model</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>----------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
<td>---------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Individual counselling at the cancer centre</td>
<td>132, 68% [61-75%]</td>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Site 1</td>
<td>37 (60%)</td>
<td>( \chi^2(2) = 6.9, p = 0.0320 )</td>
<td>( \chi^2(2) = 7.9, p = 0.0197^* )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Site 2</td>
<td>65 (78%)</td>
<td>2.4 (1.2-5.1)</td>
<td>2.7 (1.3-5.7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Site 4</td>
<td>30 (63%)</td>
<td>1.1 (0.5-2.4)</td>
<td>1.2 (0.5-2.6)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td>18-49 years</td>
<td>33 (85%)</td>
<td>( \chi^2(3) = 8.1, p = 0.0445 )</td>
<td>( \chi^2(3) = 69.0, p = 0.0287^* )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50-59 years</td>
<td>24 (71%)</td>
<td>0.4 (0.1-1.4)</td>
<td>0.4 (0.1-1.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>60-69 years</td>
<td>41 (66%)</td>
<td>0.4 (0.1-1.0)</td>
<td>0.3 (0.1-0.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>70 years plus</td>
<td>34 (59%)</td>
<td>0.3 (0.1-0.7)</td>
<td>0.2 (0.1-0.7)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td>Male</td>
<td>66 (67%)</td>
<td>( \chi^2(1) = 0.3, p = 0.5962 )</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td>66 (70%)</td>
<td>1.2 (0.6-2.2)</td>
<td></td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td></td>
<td>Breast</td>
<td>40 (75%)</td>
<td>( \chi^2(2) = 1.9, p = 0.3932 )</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prostate</td>
<td>28 (64%)</td>
<td>0.6 (0.2-1.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other/don't know</td>
<td>64 (67%)</td>
<td>0.7 (0.3-1.4)</td>
<td></td>
</tr>
<tr>
<td>Living with a partner</td>
<td></td>
<td>No</td>
<td>48 (65%)</td>
<td>( \chi^2(1) = 0.7, p = 0.4072 )</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>84 (71%)</td>
<td>1.3 (0.7-2.4)</td>
<td></td>
</tr>
<tr>
<td>Anxiety b</td>
<td></td>
<td>No</td>
<td>111 (66%)</td>
<td>( \chi^2(1) = 2.3, p = 0.1293 )</td>
<td>( \chi^2(1) = 0.4, p = 0.5246 )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>21 (81%)</td>
<td>2.1 (0.8-5.9)</td>
<td>0.6 (0.1-2.8)</td>
</tr>
<tr>
<td>Depression b</td>
<td></td>
<td>No</td>
<td>128 (69%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes</td>
<td>4 (57%)</td>
<td>0.6 (0.1-2.8)</td>
<td></td>
</tr>
<tr>
<td>Type of support</td>
<td>Patients indicating they would accept or currently were accepting support n, % [95% CI]</td>
<td>Characteristic</td>
<td>Patient in each category indicating they would accept or currently were accepting support n (%)</td>
<td>Univariate analysis LR Chi², p</td>
<td>Final multiple logistic regression model Hosmer Lemeshow p LR Chi², p</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Treatment/ counselling from my cancer doctor</td>
<td>157, 81% [75-87%]</td>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>47 (76%)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Site 2</td>
<td>68 (82%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td>42 (88%)</td>
<td></td>
<td></td>
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<tr>
<td>Age group</td>
<td></td>
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<tr>
<td>18-49 years</td>
<td>30 (77%)</td>
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<td>50-59 years</td>
<td>28 (82%)</td>
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<tr>
<td>60-69 years</td>
<td>49 (79%)</td>
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<tr>
<td>70 years plus</td>
<td>50 (86%)</td>
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<tr>
<td>Sex</td>
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<tr>
<td>Male</td>
<td>81 (82%)</td>
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<tr>
<td>Female</td>
<td>76 (81%)</td>
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<tr>
<td>Cancer diagnosis</td>
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</tr>
<tr>
<td>Breast</td>
<td>43 (81%)</td>
<td></td>
<td></td>
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<tr>
<td>Prostate</td>
<td>37 (84%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Other/don't know a</td>
<td>77 (80%)</td>
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<tr>
<td>Living with a partner</td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>60 (81%)</td>
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<tr>
<td>Yes</td>
<td>97 (82%)</td>
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<tr>
<td>Anxiety b</td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>135 (81%)</td>
<td></td>
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<td></td>
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<tr>
<td>Yes</td>
<td>22 (85%)</td>
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<tr>
<td>Depression b</td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>151 (81%)</td>
<td></td>
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<tr>
<td>Yes</td>
<td>6 (86%)</td>
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<td></td>
</tr>
<tr>
<td>Type of support</td>
<td>Univariate analysis</td>
<td>Final multiple logistic regression model</td>
<td></td>
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<tr>
<td></td>
<td>LR Chi², p</td>
<td>LR Chi², p</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Unadjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>p = 0.9237</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group counselling outside the cancer centre</td>
<td></td>
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</tr>
<tr>
<td>Patient in each category indicating they would accept or current were accepting support</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>n (%)</td>
<td>χ²(2) = 1.5, p = 0.4750</td>
<td>χ²(2) = 1.5, p = 0.4663</td>
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<tr>
<td>Hospital</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Site 1</td>
<td>16 (26%)</td>
<td>1.5 (0.7-3.0)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 2</td>
<td>28 (34%)</td>
<td>1.6 (0.7-3.6)</td>
<td>1.5 (0.7-3.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td>17 (35%)</td>
<td>1.6 (0.7-3.8)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49 years</td>
<td>16 (41%)</td>
<td>1.3 (0.5-3.2)</td>
<td>1.2 (0.5-3.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td>16 (47%)</td>
<td>0.6 (0.3-1.5)</td>
<td>0.6 (0.3-1.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69 years</td>
<td>19 (31%)</td>
<td>0.3 (0.1-0.8)</td>
<td>0.3 (0.1-0.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 years plus</td>
<td>10 (17%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28 (28%)</td>
<td>1.4 (0.7-2.5)</td>
<td>1</td>
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</tr>
<tr>
<td>Female</td>
<td>33 (35%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>16 (30%)</td>
<td>0.9 (0.4-2.1)</td>
<td>1.2 (0.6-2.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>12 (27%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/don't know</td>
<td>33 (34%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Living with a partner</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>18 (24%)</td>
<td>1.8 (0.9-3.4)</td>
<td>1</td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>43 (36%)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>49 (29%)</td>
<td>2.1 (0.9-4.8)</td>
<td>1</td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>12 (46%)</td>
<td></td>
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</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>58 (31%)</td>
<td>1.7 (0.4-7.6)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (43%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of support</td>
<td>Characteristic</td>
<td>Patient in each category indicating they would accept or current were accepting support n (%)</td>
<td>Univariate analysis LR Chi², p Unadjusted OR (95% CI)</td>
<td>Final multiple logistic regression model Hosmer Lemeshow p LR Chi², p Adjusted OR (95% CI)</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------</td>
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<td>-----------------------------------------------------------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>Individual counselling outside the cancer centre</td>
<td></td>
<td>102, 53% [46-60%]</td>
<td></td>
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<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td></td>
<td>33 (53%)</td>
<td>$\chi^2(2) = 0.2, p = 0.8949^a$</td>
<td>$\chi^2(2) = 0.2, p = 0.9083$</td>
<td></td>
</tr>
<tr>
<td>Site 2</td>
<td></td>
<td>45 (54%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td></td>
<td>24 (50%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49 years</td>
<td></td>
<td>25 (64%)</td>
<td>$\chi^2(3) = 10.3, p = 0.0160^c$</td>
<td>$\chi^2(3) = 10.3, p = 0.0162^* $</td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td></td>
<td>23 (68%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69 years</td>
<td></td>
<td>32 (52%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 years plus</td>
<td></td>
<td>22 (38%)</td>
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<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>45 (45%)</td>
<td>$\chi^2(1) = 4.5, p = 0.0343^a,^d$</td>
<td>$\chi^2(1) = 4.5, p = 0.0343^a,^d$</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>57 (49%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Cancer diagnosis</td>
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<tr>
<td>Breast</td>
<td></td>
<td>35 (66%)</td>
<td>$\chi^2(2) = 5.7, p = 0.0566^a,^d$</td>
<td>$\chi^2(2) = 5.7, p = 0.0566^a,^d$</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td></td>
<td>19 (43%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/don't know a</td>
<td></td>
<td>48 (50%)</td>
<td></td>
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</tr>
<tr>
<td>Living with a partner</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td></td>
<td>37 (50%)</td>
<td>$\chi^2(1) = 0.4, p = 0.5318$</td>
<td>$\chi^2(1) = 0.4, p = 0.5318$</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>65 (55%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety b</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>No</td>
<td></td>
<td>86 (52%)</td>
<td>$\chi^2(1) = 0.9, p = 0.3376$</td>
<td>$\chi^2(1) = 0.9, p = 0.3376$</td>
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</tr>
<tr>
<td>Yes</td>
<td></td>
<td>16 (62%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression b</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td></td>
<td>97 (52%)</td>
<td>$\chi^2(1) = 1.05, p = 0.3066$</td>
<td>$\chi^2(1) = 1.05, p = 0.3066$</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>5 (71%)</td>
<td></td>
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</tr>
<tr>
<td>Type of support</td>
<td>Patients indicating they would accept or currently were accepting support n, % [95% CI]</td>
<td>Characteristic</td>
<td>Patient in each category indicating they would accept or current were accepting support n (%)</td>
<td>Univariate analysis LR Chi², p Unadjusted OR (95% CI)</td>
<td>Final multiple logistic regression model Hosmer Lemeshow p LR Chi², p Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>---------------------------------------------</td>
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<td>---------------------------------------------------------------------------------------------</td>
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<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Treatment/ counselling from my GP</td>
<td>137, 71% [64-77%]</td>
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<tr>
<td>Hospital</td>
<td></td>
<td></td>
<td></td>
<td>χ²(2) = 2.8, p = 0.2426</td>
<td>χ²(3) = 2.87, p = 0.2379</td>
</tr>
<tr>
<td>Site 1</td>
<td>39 (63%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Site 2</td>
<td>62 (75%)</td>
<td></td>
<td></td>
<td>1.7 (0.9-3.6)</td>
<td>1.7 (0.8-3.5)</td>
</tr>
<tr>
<td>Site 4</td>
<td>36 (75%)</td>
<td></td>
<td></td>
<td>1.8 (0.8-4.1)</td>
<td>1.9 (0.8-4.3)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td>χ²(3) = 0.7, p = 0.8678</td>
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</tr>
<tr>
<td>18-49 years</td>
<td>28 (72%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>50-59 years</td>
<td>26 (76%)</td>
<td></td>
<td></td>
<td>1.3 (0.4-3.7)</td>
<td>1.3 (0.4-3.7)</td>
</tr>
<tr>
<td>60-69 years</td>
<td>43 (69%)</td>
<td></td>
<td></td>
<td>0.9 (0.4-2.1)</td>
<td>0.9 (0.4-2.1)</td>
</tr>
<tr>
<td>70 years plus</td>
<td>40 (69%)</td>
<td></td>
<td></td>
<td>0.9 (0.4-2.1)</td>
<td>0.9 (0.4-2.1)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td>χ²(1) = 1.9, p = 0.1740</td>
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</tr>
<tr>
<td>Male</td>
<td>66 (67%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
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<tr>
<td>Female</td>
<td>71 (76%)</td>
<td></td>
<td></td>
<td>1.5 (0.8-2.9)</td>
<td>1.5 (0.8-2.9)</td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td>χ²(2) = 1.1, p = 0.5795</td>
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</tr>
<tr>
<td>Breast</td>
<td>40 (75%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Prostate</td>
<td>32 (72%)</td>
<td></td>
<td></td>
<td>0.9 (0.3-2.1)</td>
<td>0.9 (0.3-2.1)</td>
</tr>
<tr>
<td>Other/don't know a</td>
<td>65 (68%)</td>
<td></td>
<td></td>
<td>0.7 (0.3-1.5)</td>
<td>0.7 (0.3-1.5)</td>
</tr>
<tr>
<td>Living with a partner</td>
<td></td>
<td></td>
<td></td>
<td>χ²(1) = 1.3, p = 0.2540</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>56 (76%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>81 (68%)</td>
<td></td>
<td></td>
<td>0.7 (0.4-1.3)</td>
<td>0.7 (0.4-1.3)</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
<td>χ²(1) = 5.2, p = 0.0228</td>
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</tr>
<tr>
<td>No</td>
<td>114 (68%)</td>
<td></td>
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<td>1</td>
<td>1</td>
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<tr>
<td>Yes</td>
<td>23 (98%)</td>
<td></td>
<td></td>
<td>3.6 (1.0-12.4)</td>
<td>3.6 (1.0-12.4)</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td>χ²(1) = 0.00, p = 0.9789</td>
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</tr>
<tr>
<td>No</td>
<td>132 (71%)</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (71%)</td>
<td></td>
<td></td>
<td>1.0 (0.2-5.4)</td>
<td>1.0 (0.2-5.4)</td>
</tr>
<tr>
<td>Type of support</td>
<td>Patients indicating they would accept or currently were accepting support</td>
<td>Characteristic</td>
<td>Patient in each category indicating they would accept or current were accepting support</td>
<td>Univariate analysis</td>
<td>Final multiple logistic regression model</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
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<td>------------------------------------------------------------------------------------</td>
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<td>----------------------------------------</td>
</tr>
<tr>
<td><strong>Online/Internet support</strong></td>
<td>49, 25% [19-32%]</td>
<td><strong>Characteristic</strong></td>
<td><strong>Patient in each category indicating they would accept or current were accepting support</strong></td>
<td><strong>Unadjusted OR (95% CI)</strong></td>
<td><strong>Adjusted OR (95% CI)</strong></td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td><strong>Univariate analysis</strong></td>
<td><strong>Final multiple logistic regression model</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>15 (24%)</td>
<td>$\chi^2(2) = 0.1, p = 0.9487$</td>
<td>$\chi^2(2) = 0.1, p = 0.9533$</td>
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</tr>
<tr>
<td>Site 2</td>
<td>22 (27%)</td>
<td>$\chi^2(2) = 0.1, p = 0.9487$</td>
<td>$\chi^2(2) = 0.1, p = 0.9533$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td>12 (25%)</td>
<td>$\chi^2(2) = 0.1, p = 0.9487$</td>
<td>$\chi^2(2) = 0.1, p = 0.9533$</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001$</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49 years</td>
<td>16 (41%)</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001$</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td>15 (44%)</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001$</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69 years</td>
<td>14 (23%)</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001$</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 years plus</td>
<td>4 (6.9%)</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001$</td>
<td>$\chi^2(3) = 23.9, p &lt; 0.0001^*$</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>27 (27%)</td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>22 (23%)</td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td>$\chi^2(1) = 0.4, p = 0.5368$</td>
<td></td>
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</tr>
<tr>
<td><strong>Cancer diagnosis</strong></td>
<td></td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>10 (19%)</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>12 (27%)</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/don’t know a</td>
<td>27 (28%)</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td>$\chi^2(2) = 1.72, p = 0.4230$</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Living with a partner</strong></td>
<td></td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>17 (23%)</td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32 (27%)</td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td>$\chi^2(1) = 0.4, p = 0.5414$</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety b</strong></td>
<td></td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>38 (23%)</td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (42%)</td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td>$\chi^2(1) = 4.2, p = 0.0417$</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Depression b</strong></td>
<td></td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>46 (25%)</td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (43%)</td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td>$\chi^2(1) = 1.1, p = 0.3055$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note.** Observations within each variable may not add to the total due to missing values

- a. Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types
b. Assessed using the Hospital Anxiety and Depression Scale (HADS)
c. Included in initial multiple logistic regression model
d. Eliminated during backwards stepwise multiple logistic regression analysis
S6: Number and proportion (with 95% CIs) of patients indicating that if experiencing anxiety or depression, they would be willing to accept professional support, by distress assessment method ($n = 193$)

<table>
<thead>
<tr>
<th>Distress assessment method ($n$)</th>
<th>Combined willingness to accept support $n$</th>
<th>% (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS mild-severe anxiety and depression ($n = 66$)</td>
<td>62</td>
<td>94% (85-98%)</td>
</tr>
<tr>
<td>HADS moderate-severe anxiety and depression ($n = 29$)</td>
<td>27</td>
<td>93% (77-99%)</td>
</tr>
<tr>
<td>Perceived mild-severe anxiety and depression ($n = 109$)</td>
<td>103</td>
<td>94% (88-98%)</td>
</tr>
<tr>
<td>Perceived moderate-severe anxiety and depression ($n = 33$)</td>
<td>33</td>
<td>100% (89-100%)</td>
</tr>
<tr>
<td>Patient preference to be offered professional support for current levels of anxiety and/or depression ($n = 54$)</td>
<td>54</td>
<td>100% (93-100%)</td>
</tr>
</tbody>
</table>
The World Health Organization aims to improve subjective well-being and quality of life through increased “responsiveness” to patients’ values and expectations for care, a process consistent with existing definitions of patient-centred care [1]. Provision of high-quality patient-centred care is thought to impact on the well-being of cancer patients [2]. Assessing patients’ perceptions of where improvements in patient-centred care would improve their well-being most may be a useful approach for prioritising quality-improvement initiatives. This approach may be particularly valuable where multiple domains of patient-centred care are in need of improvement, and the health system has limited resources to respond. Paper Five describes radiation oncology outpatients’ perceptions of patient-centred care in domains of patient-centred care important from the perspective of cancer patients. Specifically, patients were asked to indicate whether better care in each of eight identified domains of patient-centred care would have greatly improved their well-being. The proportions and characteristics of patients endorsing specific and multiple domains where they perceived that better care could lead to improvements in their well-being are reported in Paper Five.

This paper was published in *BMJ Open* (see Appendix 5.1).

References


Radiation oncology outpatient perceptions of patient-centred care: A cross-sectional survey

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2. Hunter Medical Research Institute, Newcastle, Australia

3. Centre for Clinical Epidemiology and Biostatistics, School of Medicine and Public Health, Faculty of Health, University of Newcastle, Callaghan, New South Wales 2308, Australia
5.1 Abstract

Objectives
We aimed to describe the proportion and characteristics of cancer patients who perceived that better care would have greatly improved their wellbeing in (1) specific, and (2) multiple domains of patient-centred care.

Design
Cross-sectional touchscreen computer survey.

Setting
Four Australian radiation therapy departments located within major urban public hospitals.

Participants
Radiation therapy outpatients were invited to participate in a touchscreen computer survey. Eligible patients were aged at least 18 years old, diagnosed with cancer, and had sufficient English to complete the survey.

Primary outcome measure
Participants were asked whether their wellbeing could have been greatly improved if better care had been provided across eight domains of patient-centred care. Characteristics of those respondents who identified (1) specific and (2) multiple domains where it was perceived that better care would have greatly improved their well-being, were examined.

Results
Of 508 eligible radiation therapy patients, 344 (68%) completed the survey. Patients most frequently perceived that better care in the following domains could have improved their wellbeing: information and communication about their cancer (22%;
95% CI 18 to 27%); emotional and spiritual support (22%; 95% CI 18 to 27%); management of physical symptoms (21%; 95% CI 17 to 26%); and involvement of friends and family (21%; 95% CI 17 to 26%). Just under one third of respondents (31%; 95% CI 26 to 36%) indicated that their wellbeing could have been improved by better care across two or more domains of care. Patients in younger age groups and migrants to Australia had higher odds of endorsing multiple domains where better care would have improved their wellbeing.

Conclusions

Further investigation of patients’ perceptions of how their perceived quality of care might be improved is warranted, particularly amongst patients in younger age groups and migrants to Australia.
5.1.1 Summary

Article focus

- The Institute of Medicine has indicated the urgency of evaluating and improving the quality of health care, including patient-centred care.
- We aimed to describe the proportion and characteristics of radiation oncology outpatients who perceived that better care would have greatly improved their wellbeing in (1) specific, and (2) multiple domains of patient-centred care.

Key messages

- Just under one third of cancer patients undergoing radiation therapy treatment indicated that their wellbeing could have been greatly improved by better care across multiple domains of patient-centred care.
- Younger patients and migrants to Australia were more likely to identify that better care in multiple domains would be of benefit to their wellbeing, suggesting that targeted interventions to improve patient-centred care and wellbeing outcomes for these groups is required.

Strengths and limitations

- This study involved radiation oncology outpatients with heterogeneous cancer diagnoses, providing treatment centres with guidance about which patient groups may perceive the need for better care in specific and multiple domains of patient-centredness.
- The quality of care measure used appeared to have good face validity and internal reliability; however, further examination of its psychometric properties is needed.
5.2 Introduction

Why assess patient views of quality of care?

The Institute of Medicine (IOM) in the USA, an independent organisation for gathering evidence to assist health decision making, has indicated the urgency of assessing and improving the quality of health care [1]. Quality health care is care that is safe, timely, effective, efficient, equitable and patient-centred [2]. A patient-centred approach to care is defined as being respectful of, and responsive to, patients’ physical, social and emotional preferences and needs [3]. Provision of patient-centred care may contribute to improvements in patients’ physical, mental and social well-being [4, 5]. A patient-centred approach to care is now endorsed as a key component of quality health care by many organisations (including the WHO [6]) and governments (e.g. in Australia, the USA, the UK, Canada, Germany, France, the Netherlands and Switzerland [7]). Although quality of care is often examined through audit and benchmarking of clinical outcomes data [8], examining patients’ judgements of how their experiences of care correspond with their preferences and needs is required in order to assess the quality of patient-centred care [9].

What has previous patient-centred care research contributed to knowledge about prioritising quality improvement efforts?

Quality of patient-centred care has been assessed using a variety of patient reported outcomes measures including surveys of patient satisfaction and experiences which are closely linked to the IOM patient-centred care conceptual framework [10, 11]. Patient satisfaction surveys have been criticised because responses may be heavily dependent upon patients’ expectations of care, leading to the development of patient experience surveys [10]. The Picker Institute survey assesses outpatients’ experiences of care across the domains of patients’ preferences, emotional support, physical
comfort, information and education, coordination of care, access to care, and involvement of family/friends [10, 12, 13]. Recently, indicators of the quality of patient-centred care have been developed from international patient-centred oncology clinical practice guidelines [11, 14]. These indicators have been grouped across the domains of information; coordination/organisation of care; physical support; emotional and psychological support; communication and respect; involvement; access; and follow-up/after-care. To date, these approaches have not attempted to capture patient perceptions of the degree to which their wellbeing would benefit from improved care across these different domains [15]. Drawing upon the formal supportive care needs assessment approach which aims to identify the level of patient need for help [16], identification of patients’ views of the relative benefit that would be conferred by improvements in different patient-centred domains care may assist with identifying and prioritising quality improvement efforts [11].

Some subgroups of patients may perceive that they receive poorer care than others. For instance, older patients may be more likely than younger patients to express satisfaction with care, possibly relating to differences in the expectations for care provision [17]. Additionally, cancer patients who have clinically significant levels of anxiety have been found to give lower ratings of satisfaction with care [18]. Wellbeing in patients diagnosed with chronic illness may be linked to aspects of social support such as having a partner, [19] and also potentially to ethnicity [20]. Given that there is some evidence of increased psychological distress and supportive care needs prior to and during cancer treatment [21, 22], it may also be that treatment stage may impact on perceptions of care.
Patient-centred care for radiation therapy patients

It is recommended that approximately 50% of cancer patients undergo radiation therapy treatment [23]. Given that this treatment is often characterised by frequent contact with the healthcare system over the course of treatment, the radiation therapy setting provides an opportunity for addressing patient perceived needs across the multiple domains of patient-centred care [23]. Although research into specific domains and specific cancer types has been conducted in radiotherapy settings [21, 24, 25], to the best of our knowledge, this is the first study to ask cancer patients undergoing radiation therapy about their perceptions of how better care across multiple patient-centred domains could improve their wellbeing [26]. Further, no previous studies have identified characteristics of radiation therapy patients who are likely to perceive better patient-centred care [27].

This study aimed to examine the proportion and characteristics of radiation therapy patients who indicate that their wellbeing could have been greatly improved by better cancer care across each of eight domains of patient-centred care. We also aimed to assess characteristics associated with a patient perception that better care across multiple domains of patient-centred care would have improved their wellbeing.

5.3 Methods

Ethics approvals

Ethics approval was obtained from the University of Newcastle and NSW Population and Health Services Research Ethics Committees.

Design

A cross-sectional survey was completed using touchscreen computers.
Participants

Radiation oncology outpatients were recruited from four radiation therapy departments in a major urban centre in Australia between March and December 2010. Each radiation therapy department was attached to a major public teaching hospital, and had at least three Linear Accelerators available for treatment. Eligible patients were aged 18 years or older; diagnosed with cancer, and had sufficient command of English to complete the touchscreen computer survey. Patients who were receiving both radical and palliative treatment were eligible. Those who were attending the clinic for the first time or who were considered by clinic staff to be too unwell or unable to give informed consent were excluded.

Procedure

Patients waiting for a radiation therapy treatment were invited to participate in the study by a research assistant. Consenting patients were given a unique identification code to login to the touchscreen computer questionnaire. If patients were called into their treatment before finishing their survey, they had the option of resuming after their treatment. Touchscreen computer surveys have been reported as being faster and easier to use for outpatients than pencil and paper surveys,[28] and have been found to be acceptable to oncology patients [29].

Measures

Digivey survey software (CREOSO - Digivey Survey Center, Phoenix, Arizona) was used to programme the patient survey, which was administered using Dell Latitude XT2 touchscreen laptop computers.
**Quality of care: patient-centred care**

Questions and domain descriptions were developed to correspond with domains of patient-centred care described in the literature [10, 11], ensuring face validity of the items and clinical relevance to patients currently undergoing treatment. Survey items were extensively pilot tested and modified based on feedback from 67 patients. Eight items, each assessing a different domain of care, were presented on separate screens with the stem, "During my cancer care, my wellbeing would have been greatly improved by." Table 5.1 lists the eight items and a short description of each domain that was presented at the bottom of the touchscreen. Patients were asked to indicate their level of agreement with each statement on a four-point Likert scale (Strongly disagree, Disagree, Agree, Strongly agree). Internal consistency of the items was assessed using Cronbach’s α.

**Demographic characteristics**

Patient self-report was used to collect age, gender, whether participants were born in Australia, living with a partner and the postcode of participants' usual place of residence.

**Disease characteristics**

A multiple choice question, “What is your most recent primary cancer diagnosis?”, was used to determine respondents' most recent primary cancer diagnosis. Common cancer types were listed on screen, along with the categories "Other–please specify" and "Don't know". Approximate time since diagnosis was calculated from patient self-reported year and month of diagnosis and their recruitment date. Patients were asked to indicate the number of radiation therapy treatment and outpatient appointments they had attended, whether they had experienced a second diagnosis and/or recurrence, and whether they perceived that the aim of their treatment was to cure the cancer,
prevent the cancer from coming back or control symptoms of cancer (cure is not possible).

**Psychological characteristics**

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of anxiety and depression [30]. Both the anxiety and depression subscales provide scores of between 0 and 21 where 0-7 = Normal, 8-10 = Mild, 11-14 = Moderate, and 15-21 = Severe. The scale has been utilised in research and in clinical practice [31], with demonstrated reliability and validity [32]. HADS scores have been found to be comparable when administered by touchscreen computer and pen-and-paper in a population of patients with cancer [33].

**Statistical methods**

Radiation therapy patients were defined as having endorsed each domain if they indicated that they “agreed” or “strongly agreed” that better care would have greatly improved their well-being. The proportion of patients endorsing each domain was reported with 95% CIs. Respondents were then dichotomised on the basis of (1) 0-1 domains endorsed or (2) multiple (2 or more) domains endorsed. Univariate logistic analysis was used to investigate the relationship between demographic characteristics, disease factors and psychological distress and patient endorsement of (1) each of the eight domains of care and (2) multiple (2 or more) domains of care requiring improvement. The explanatory variables examined included age (18-49, 50-59, 60-69, 70 plus), sex (male, female), cancer diagnosis (Breast, Prostate, Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian born (no, yes), living with a partner (no, yes), anxiety (no, yes), depression (no, yes), usual place of residence (urban/rural, based on the Accessibility/Remoteness Index of Australia (ARIA+) score), socioeconomic status (SES) (Socio-Economic Indexes for Areas average scores [34]),
and number of radiotherapy treatment appointments attended (continuous measure). Variables with a \( p \) value of 0.2 or less on the univariate likelihood ratio test were included in the multiple logistic regression model. The backwards stepwise method was then used to remove all variables with a \( p \) value of 0.1 or more on the likelihood ratio test, with the recruitment site included in all multiple regression models. The fit of the final model was assessed using the Hosmer-Lemeshow goodness of fit test. For individual domains, ORs with 95% CIs are reported for multiple regression models. For the assessment of characteristics associated with endorsing multiple domains, ORs with 95% CIs are reported for univariate and multiple regression models. Analysis was conducted using STATA V.11.2, and a significance level of 0.05 was used.

**Sample size and statistical power**

We aimed to recruit a total of 450 patients which, based on 50% of patients perceiving the need for better care in each domain, would allow us to obtain prevalence estimates with 95% CIs within ±5% of the point estimate. This sample size would also be sufficient to detect differences of approximately 15% in characteristics between those who perceive the need for better care in each individual domain and also multiple domains of care, with 80% power and 5% significance level.
<table>
<thead>
<tr>
<th>Item</th>
<th>On screen description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better management of my physical symptoms</td>
<td>May relate to your pain, sleeplessness, other side-effects and symptoms</td>
</tr>
<tr>
<td>Better information and communication about my cancer and care</td>
<td>May include clear and consistent information about your diagnosis, test results, treatment, taking medications, food you should be eating, exercise you can do safely etc.</td>
</tr>
<tr>
<td>Better emotional and/or spiritual support</td>
<td>May include services or support to help you cope with the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body images etc.</td>
</tr>
<tr>
<td>Better services, information and support for my friends/family</td>
<td>May include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care.</td>
</tr>
<tr>
<td>Better staff approachability and respect for me</td>
<td>Describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions.</td>
</tr>
<tr>
<td>Getting better access to the care I need when required</td>
<td>Describes not having to wait too long to get appointments, and having treatment and medical advice available when needed.</td>
</tr>
<tr>
<td>Better services/support to cope with changes to my relationships</td>
<td>May include knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships.</td>
</tr>
<tr>
<td>Better services/advice to assist me with practical concerns</td>
<td>May include being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues.</td>
</tr>
</tbody>
</table>
5.4 Results

Of the 639 patients screened for eligibility, 110 were ineligible due to: inadequate English (n=51); not currently receiving RT (n = 32); had already been approached about the study (n = 6); not being diagnosed with cancer (n = 3); clinic staff concern about patient burden or ability to give informed consent (n = 3); being aged under 18 (n = 2), or no specified reason (n=13). Of the 529 eligible patients, 85% (n = 451) consented, and 69% (n = 365) completed the survey. Incomplete surveys were primarily because patients were called into their treatment appointment before survey completion, and no data were available from these surveys. An additional 21 patients were excluded because they reported that they were attending their first RT treatment. Once these participants were ruled ineligible, the overall response rate was 68% of 508 eligible radiation therapy patients. Table 5.2 shows the characteristics of the 344 respondents. 51% were men, the median age was 63.3 (Quartile [Q] 1: 52.2, Q3: 70.5) and the median number of weeks since diagnosis was 27.6 (Q1: 16.0, Q3: 57.3). The majority of respondents (97%) were currently receiving radiation therapy treatment, with the remainder reporting that they were attending the treatment centre for a check-up. The distribution of primary cancer type within the sample can be seen in Table 5.2.

Internal consistency of items

When considering the items with responses on a four-point Likert scale, the internal consistency (Cronbach’s α) was 0.92. When the responses were dichotomised (agree versus disagree), Cronbach’s α was 0.89.

Proportion of patients endorsing individual domains of patient-centred care

Table 5.3 shows the number and proportion of radiation oncology patients who agreed that their wellbeing could have been improved by better care across eight different
domains of patient-centred care. It can be seen that each domain was endorsed by between 12% and 22% of patients.

**Characteristics associated with endorsement of domains**

Multiple logistic regression analysis identified that Australian born participants had lower odds of endorsing perceiving “better management of physical symptoms” would have greatly improved their wellbeing (OR = 0.4; 95% CI 0.2 to 0.7; \( p = 0.0008 \)). No other characteristics were significantly associated with endorsing better management of physical symptoms.

**Better information and communication about my cancer and care**

Australian born patients had lower odds of perceiving that “better information and communication about my cancer and care” would have greatly improved their wellbeing (OR = 0.5; 95% CI 0.3 to 0.9; \( p = 0.0153 \)), as did patients living with a partner (OR = 0.5; 95% CI 0.3 to 0.8; \( p = 0.0083 \)). It was also found that patients aged 60-69 years (OR = 0.3; 95% CI 0.1 to 0.7) and aged 70 or over (OR = 0.3; 95% CI 0.2 to 0.8) had lower odds of endorsing this domain than younger participants (\( p = 0.0042 \)). Patients with a likely presence of depression had three times the odds of endorsing this domain (OR = 3.1; 95% CI 1.1 to 9.0; \( p = 0.0396 \)).

**Better emotional and/or spiritual support**

Patients aged 60-69 years (OR = 0.3; 95% CI 0.1 to 0.6) and aged 70 or over (OR = 0.4; 95% CI 0.2 to 0.8) had lower odds of endorsing this domain than younger participants (\( p = 0.0011 \)). Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95% CI 0.2 to 0.5; \( p < 0.0001 \)), whilst patients with clinically significant levels of depression had higher odds of endorsing (OR = 3.5; 95% CI 1.2 to 10.1; \( p = 0.0250 \)).
Better services, information and support for my friends/family

Lower odds of endorsing this domain were found in older patients aged 60-69 years (OR = 0.2; 95% CI 0.1 to 0.5) and aged 70 or over (OR = 0.2; 95% CI 0.1 to 0.4) compared with younger participants (p < 0.0001), and also in Australian born patients (OR = 0.4; 95% CI 0.2 to 0.6; p = 0.0004).

Better staff approachability and respect for me

Australian born patients had significantly lower odds of endorsing this domain (OR = 0.3; 95% CI 0.1 to 0.5; p = 0.0001). Marginally non-significantly lower odds of endorsing this domain were found in older patients aged 60-69 years (OR = 0.3; 95% CI 0.1 to 0.9) compared with younger participants (p = 0.0683).

Getting better access to the care I need when required

Older patients aged 60-69 years (OR = 0.2; 95% CI 0.1 to 0.5) and aged 70 or over (OR = 0.3; 95% CI 0.1 to 0.8) had lower odds of endorsing this domain compared to younger participants (p = 0.0003). Once again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95% CI 0.2 to 0.6; p = 0.0003). Marginally non-significantly lower odds were also found in socioeconomic Group 2 (OR = 0.2; 95% CI 0.1 to 0.9) and Group 3 (OR = 0.3; 95% CI 0.1 to 0.9) compared with the lowest socioeconomic Group 1 (p = 0.0837).

Better services/support to cope with changes to my relationship

Older patients aged 60-69 years (OR = 0.1; 95% CI 0.1 to 0.4) and aged 70 or over (OR = 0.2; 95% CI 0.1 to 0.4) had lower odds of endorsing this domain compared with younger participants (p < 0.0001). Once again, Australian born patients had lower odds of endorsing this domain (OR = 0.3; 95% CI 0.1 to 0.5; p = 0.0001). Patients with clinically significant levels of depression had higher odds of endorsing this domain (OR = 7.2; 95% CI 2.3 to 22.5; p = 0.0007).
**Better services/advice to assist me with practical concerns**

Older patients aged 60-69 years (OR = 0.1; 95% CI 0.1 to 0.3) and aged 70 or over (OR = 0.3; 95% CI 0.1 to 0.6) had lower odds of endorsing this domain compared with younger participants ($p < 0.0001$). Australian born patients also had lower odds of endorsing this domain (OR = 0.5; 95% CI 0.3 to 0.8; $p = 0.0070$).

**Proportion of patients endorsing multiple domains where better care would have improved their well-being**

Figure 5.1 shows the percentage of respondents endorsing none, one and multiple domains where better care would have improved their wellbeing. Overall, 31% of respondents ($n = 107$) endorsed multiple domains where they agreed or strongly agreed that their wellbeing could have been improved by better care.

For 55% of participants, it was perceived that improvement in wellbeing would not have resulted from better care in any of the examined domains. Fourteen percent of participants identified only one domain where better care would have greatly improved their wellbeing. Table 5.4 shows the results of analyses examining factors associated with the perception that wellbeing could have been improved by better care in multiple (2 or more) domains. It can be seen that compared with the younger age group (18-49 years), being aged 60 years or over was associated with significantly lower odds of endorsing multiple domains as requiring improvement. Additionally, relative to patients not born in Australia, those who were Australian born had significantly lower odds of endorsing multiple domains in which wellbeing would have been improved by better care. Outpatients living with a partner had significantly lower odds of identifying multiple domains where better care would have greatly improved their wellbeing. There were significantly higher odds of endorsing multiple domains amongst outpatients with a likely presence of anxiety.
Table 5.2: Demographic and disease characteristics of respondents ($n = 344$)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (min, max)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>61.4 (18.9-91.4)</td>
</tr>
<tr>
<td></td>
<td>$n$ (%)</td>
</tr>
<tr>
<td>Males</td>
<td>176 (51%)</td>
</tr>
<tr>
<td>Region of birth</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>231 (67%)</td>
</tr>
<tr>
<td>UK/Ireland</td>
<td>30 (8.7%)</td>
</tr>
<tr>
<td>Europe</td>
<td>29 (8.4%)</td>
</tr>
<tr>
<td>Asia</td>
<td>25 (7.2%)</td>
</tr>
<tr>
<td>Other</td>
<td>29 (8.4%)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td>46 (14%)</td>
</tr>
<tr>
<td>Primary cancer type</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>93 (27%)</td>
</tr>
<tr>
<td>Prostate</td>
<td>73 (21%)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>33 (9.6%)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>20 (5.8%)</td>
</tr>
<tr>
<td>Brain</td>
<td>15 (4.4%)</td>
</tr>
<tr>
<td>Lung</td>
<td>15 (4.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>89 (26%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (1.7%)</td>
</tr>
<tr>
<td>Second diagnosis/recurrence</td>
<td>96 (28%)</td>
</tr>
<tr>
<td>Completed appointments with cancer doctor</td>
<td>3 (2, 5)</td>
</tr>
<tr>
<td>Completed radiation therapy appointments</td>
<td>9 (4, 17)</td>
</tr>
<tr>
<td>Weeks since diagnosis</td>
<td>27.6 (16, 37.3)</td>
</tr>
</tbody>
</table>

*Note. Observations within each variable may not add to the total due to missing values*
Table 5.3: Proportion who reported that their wellbeing would have been improved by better care across 8 domains (n = 344)

<table>
<thead>
<tr>
<th>Domains</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and communication about my cancer and care</td>
<td>76 (22%, 18-27%)</td>
</tr>
<tr>
<td>Emotional and/or spiritual support</td>
<td>75 (22%, 18-27%)</td>
</tr>
<tr>
<td>Management of my physical symptoms</td>
<td>72 (21%, 17-26%)</td>
</tr>
<tr>
<td>Services; information and support for my friends/family</td>
<td>72 (21%, 17-26%)</td>
</tr>
<tr>
<td>Services/advice to assist me with practical concerns</td>
<td>69 (20%, 16-25%)</td>
</tr>
<tr>
<td>Access to the care I need when required</td>
<td>62 (18%, 14-23%)</td>
</tr>
<tr>
<td>Services/support to cope with changes to my relationships</td>
<td>56 (16%, 13-21%)</td>
</tr>
<tr>
<td>Staff approachability and respect for me</td>
<td>42 (12%, 8.9-16%)</td>
</tr>
</tbody>
</table>
Figure 5.1: Percentage of respondents endorsing 0–8 domains in which better care would have greatly improved their wellbeing
Table 5.4: Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvementa

<table>
<thead>
<tr>
<th>Variable</th>
<th>Multiple domains endorsed</th>
<th>LR Chi², p</th>
<th>LR Chi², p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>Unadjusted OR (95% CI) b</td>
<td>Adjusted OR (95% CI) b</td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>36 (36%)</td>
<td>5.0, p = 0.1752</td>
<td>2.9, p = 0.4002</td>
</tr>
<tr>
<td>Site 2</td>
<td>22 (23%)</td>
<td>0.5 (0.3-1.0)</td>
<td>0.6 (0.3-1.2)</td>
</tr>
<tr>
<td>Site 3</td>
<td>23 (32%)</td>
<td>0.8 (0.4-1.6)</td>
<td>0.9 (0.4-1.8)</td>
</tr>
<tr>
<td>Site 4</td>
<td>26 (34%)</td>
<td>0.9 (0.5-1.7)</td>
<td>1.0 (0.5-2.0)</td>
</tr>
<tr>
<td><strong>Age category</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-49 years</td>
<td>36 (51%)</td>
<td>35.9, p &lt;0.0001</td>
<td>28.9, p &lt;0.0001*</td>
</tr>
<tr>
<td>50-59 years</td>
<td>34 (46%)</td>
<td>0.8 (0.4-1.5)</td>
<td>0.7 (0.4-1.4)</td>
</tr>
<tr>
<td>60-69 years</td>
<td>20 (18%)</td>
<td>0.2 (0.1-0.4)</td>
<td>0.2 (0.1-0.4)</td>
</tr>
<tr>
<td>70 years plus</td>
<td>17 (19%)</td>
<td>0.2 (0.1-0.4)</td>
<td>0.2 (0.1-0.5)</td>
</tr>
<tr>
<td><strong>Sex</strong>c</td>
<td></td>
<td>2.5, p = 0.1159</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>48 (27%)</td>
<td>1.4 (0.9-2.3)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>59 (35%)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer type</strong>c</td>
<td></td>
<td>3.8, p = 0.1469</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>31 (33%)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>16 (22%)</td>
<td>0.6 (0.3-1.1)</td>
<td></td>
</tr>
<tr>
<td>Other cancer types d</td>
<td>60 (34%)</td>
<td>1.0 (0.6-1.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Second diagnosis/recurrence</strong></td>
<td></td>
<td>1.0, p = 0.3123</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>81 (33%)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26 (27%)</td>
<td>0.8 (0.5-1.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Born in Australia</strong></td>
<td></td>
<td>8.5, p = 0.0037</td>
<td>5.4, p = 0.0205*</td>
</tr>
<tr>
<td>No</td>
<td>47 (42%)</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Yes</td>
<td>60 (26%)</td>
<td>0.5 (0.3-0.8)</td>
<td>0.5 (0.3-0.9)</td>
</tr>
<tr>
<td>Variable</td>
<td>Multiple domains endorsed n (%)</td>
<td>LR Chi², p</td>
<td>LR Chi², p</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td></td>
<td>Unadjusted OR (95% CI) b</td>
<td>Adjusted OR (95% CI) b</td>
<td></td>
</tr>
<tr>
<td><strong>Socioeconomic status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5 (22%)</td>
<td>0.3, p = 0.5758</td>
<td>1.0</td>
</tr>
<tr>
<td>Medium</td>
<td>8 (16%)</td>
<td>0.7 (0.2-2.4)</td>
<td>1.0 (0.4-2.9)</td>
</tr>
<tr>
<td>High</td>
<td>59 (22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Usual place of residence</strong></td>
<td>0.3, p = 0.5758</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major city</td>
<td>87 (32%)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Regional or rural</td>
<td>19 (28%)</td>
<td>0.8 (0.5-1.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Living with partner</strong></td>
<td>5.2, p = 0.0224</td>
<td>3.9, p = 0.0481*</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>50 (38%)</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Yes</td>
<td>57 (27%)</td>
<td>0.6 (0.4-0.9)</td>
<td>0.6 (0.4-1.0)</td>
</tr>
<tr>
<td><strong>Clinically significant anxiety</strong></td>
<td>10.4, p = 0.0013</td>
<td>4.3, p = 0.0383*</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>82 (28%)</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Yes</td>
<td>25 (52%)</td>
<td>2.8 (1.5-5.2)</td>
<td>2.1 (1.0-4.1)</td>
</tr>
<tr>
<td><strong>Clinically significant depression</strong></td>
<td>5.7, p = 0.0167</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>97 (30%)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10 (59%)</td>
<td>3.3 (1.2-9.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Completed radiation therapy appointments</strong></td>
<td>0.02, p = 0.8893</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. Observations within each variable may not add to the total due to missing values.*

* p<0.05; ** p<0.01; *** p<0.001; **** p<0.0001

a p-values for the Hosmer-Lemeshow goodness of fit test were between 0.2 and 0.9 for specific domain models; and was 0.1 for the multiple domain model

b Reported p-values are from the Likelihood ratio test

c Eliminated during backwards stepwise multiple logistic regression analysis

d Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types

e Assessed using the Hospital Anxiety and Depression Scale (HADS)
5.5 Discussion

In which domains would better care greatly improve wellbeing for the most patients?

For each of the eight domains of care assessed, between 12% and 22% of respondents agreed or strongly agreed that their wellbeing would have greatly improved with better care. One fifth or more agreed that improvements to the following domains would have improved their care: better information and communication about my cancer and care (22%); better emotional and/or spiritual support (22%); better management of physical symptoms (21%); better services information and support for friends/family (21%); and better services/advice to assist with practical concerns (20%). Overall, these frequencies were lower than identified in comparable domains in recent international studies of experiences of care in patients with cancer in Australia, New Zealand, British Colombia, Canada and Europe [11, 13, 18, 35, 36]. This discrepancy may be a consequence of the differences in measures. Although past measures have assessed experiences of care or unmet need, they have not assessed the impact that patients perceive better care in these patient-centred domains would have on their wellbeing. Alternatively, the discrepancies between findings may be a result of improved delivery of patient centred care over time.

Characteristics associated with endorsing each domain of patient-centred care

Country of birth

Australian born patients had lower odds of endorsing each of the assessed domains of patient-centred care. It may be that Australian born patients perceive that they are receiving better care than migrants. Alternatively, it may be that Australian born patients have lower expectations of care and of the degree to which their wellbeing would be improved by better care [37]. Linguistic and cultural barriers to patient perceptions of high quality health care have been previously identified, highlighting the
need for responsiveness to cultural background for optimal health care delivery [37]. Although the current research was limited to patients with adequate English to complete the survey, there has been increased research attention on some of these challenges faced by people with cancer from culturally and linguistically diverse backgrounds in Australia [38, 39].

**Age group**

Older age was associated with lower odds of endorsing a need for improvement in all domains of patient-centred care, with the exception of management of physical symptoms and staff approachability and respect for the patient. This is consistent with previous studies suggesting that older age is associated with higher overall patient satisfaction ratings [40] and that older patients undergoing radiation treatment have lower information needs [24]. It may be that older patients perceive pain management and interpersonal care as a traditional role of the doctor, leading to similar perceptions about the need for improvement in these domains as held by younger age groups.

**HADS classified depression**

Patients with HADS classified depression had higher odds of endorsing the following three domains than non-depressed respondents: information and communication about cancer and care; emotional and spiritual support; and support with changes to relationships. A diagnosis of chronic disease with comorbid depression has previously been associated with perceptions of poor doctor-patient communication [41]. This may be because depressive symptoms such as negative affect may make interactions with health care providers more strained and less effective than for non-depressed patients [42, 43]. Alternatively, it may be that there are patient recall difficulties arising from depressive symptoms such as poor concentration, leading to negative patient perceptions of information provision and communication [41].
**Socioeconomic status**

Higher socioeconomic groups were found to have marginally significantly lower odds of endorsing issues relating to getting access to care when required. Patients from higher SES areas may be more likely to live in wealthier urban areas that are closer to health care facilities, and therefore have less difficulty with access [44]. Given Australia’s dispersed population, access to cancer care service delivery can be challenging for patients from lower SES areas, particularly those in rural and regional areas. This is particularly the case for accessing radiation therapy treatment, which is only available in metropolitan centres and very few major regional centres [45].

**Multiple domains of patient-centred care: Characteristics of particularly vulnerable groups**

Overall, 31% of patients indicated that better care in multiple domains of patient-centred care would have greatly improved their wellbeing. Older patients had lower odds of reporting that improvements in their care were needed in multiple domains of care. This finding has been frequently reported in patient satisfaction research [40]. It has been suggested that this may reflect differences in the expectations or preferences of care of older people compared with younger people [17]. Consistent with the findings across the individual domains of care, patients born in Australia had lower odds of endorsing multiple domains where better care would have greatly improved their wellbeing. This is consistent with findings of lower patient satisfaction that have been reported in migrant groups in international settings [37].

A significant trend towards having lower odds of reporting improvements in their care were needed was seen in those respondents living with a partner. Spranger et al [19] reported that the quality of life in individuals with chronic disease was higher amongst those with a partner. Family members and carers may play an important role in
assisting patients to navigate the health care system and may advocate on the patient’s behalf [46]. Patients’ self-management skills may also be complemented by having a support person [47]; however, these findings warrant further exploration in cancer settings [48].

As expected, an association was found between clinically significant anxiety levels and patients’ perceptions that their wellbeing could be improved by better care across multiple patient-centred domains. This is consistent with findings suggesting that individuals suffering from elevated levels of anxiety may be more likely to be critical of the health care system [49]. Alternatively, anxiety may affect interactions with health care providers and the effectiveness of help seeking behaviours, resulting in the receipt of poorer care across multiple domains. This finding suggests that there is a need to identify these patients in clinical practice and reduce their perceived room for improvement in wellbeing by alleviating their anxiety and improving their perceptions of care [50]. There have been some partially successful intervention studies conducted in radiotherapy settings [51, 52] and more generally [3] that have aimed to improve patient-centredness of care.

Strengths and limitations

The current study achieved a high consent rate compared with recent research examining cancer outpatient satisfaction with care [13], and to the best of our knowledge, it is also the first large study to assess patient-centred care in radiation therapy outpatients [53]. Heterogeneous cancer sites and stages were included to provide clinics with information about which patient groups may be missing out on elements of patient-centred care. The quality of care measure was developed following extensive pilot testing and with reference to the literature, and the domains have been supported by a recent qualitative study with radiation oncology patients [53]. Therefore,
it appears to have face validity as well as internal reliability. However, further examination of its psychometric properties is needed. Demographic information was collected via patient self-report. While the accuracy of this method has been questioned [54], it has been shown to produce reliable responses for these demographic variables [55] and is a cost effective and feasible way of collecting these data.

It should also be noted that owing to extended pilot testing and low survey completion rates, our final sample size was smaller than planned. However, given that the proportion of patients perceiving the need for better care in each domain was lower than expected, we were still able to obtain prevalence estimates with 95% CIs within ±5% of the point estimate, and detect differences of approximately 15% in characteristics between those who did and did not perceive the need for better care in each domain of care, with 80% power and 5% significance level.

Conclusions

Thirty-one percent of respondents identified that better care across multiple domains would have greatly improved their wellbeing. “Information and education”, “emotional and spiritual support”, “management of physical symptoms” and “involvement of friends and family” were the four domains most commonly identified where better care would have increased respondent wellbeing. Older patients and patients born in Australia had significantly lower odds of identifying multiple domains of patient-centred care where better care would have improved their wellbeing. This suggests that younger patients and migrants to Australia appear to be more likely to identify that better care would be of benefit to their wellbeing. Further investigation of how these factors interact with wellbeing and the provision of patient-centred care may assist in developing targeted interventions to improve outcomes for these groups.
Acknowledgements

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Competing interests

There are no disclosures from any authors.

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226


DISCUSSION
D.1 Thesis overview: A multicentre patient survey in radiotherapy settings

This thesis by publication aimed to examine radiotherapy outpatients' perceptions of cancer care, with a focus on some key issues of relevance to cancer care. It examined whether radiotherapy patients were willing to answer survey questions about life expectancy, and explored whether patients' perceived life expectancy disclosure experiences reflected their preferences. In relation to emotional distress, this thesis explored the prevalence of anxiety and depression as measured by the Hospital Anxiety and Depression Scale (HADS) [1], general psychological distress, self-perceived distress levels, and desire to be offered and accept support for anxiety or depression. Finally, patients' perceptions of patient-centred care were examined, and factors associated with perceiving the need for improvement in multiple domains (compared with a single domain only) were explored.

This thesis by publication presented the findings of a number of studies completed within a multicentre survey of patients' perceptions of cancer care. Cancer patients receiving radiotherapy were recruited from the treatment waiting rooms of four New South Wales (NSW) metropolitan public hospitals during 2010. Consenting patients were asked to complete a touch screen computer survey. Different survey modules included questions related to respondents' demographic characteristics, disease characteristics, perceptions of the quality of their cancer care, psychological distress, access to care, life expectancy communication preferences, and acceptability of the survey. Overall, with a response rate of 86%, 469 surveys were completed by radiation oncology outpatients.
D.1.1 Key thesis findings

**Key finding one**

Survey questions about communication preferences and experiences related to the potentially sensitive topic of life expectancy appeared to be acceptable to radiotherapy patients. A patient-centred approach to life expectancy disclosure is recommended by consensus guidelines in Australia [2]. This was also the preference of the majority of cancer patients in this sample, with 86% of respondents preferring their clinician to ask them before discussing life expectancy. There was very poor agreement between patients’ preferences for and self-reported experiences of life expectancy disclosure (Cohen’s $\kappa = -0.04$), with only 60% observed agreement between respondents’ reported experiences of life expectancy disclosure and their preferences for these discussions. These findings indicate that there is room to improve the patient-centredness of life expectancy disclosure to radiation oncology outpatients.

**Key finding two**

The reported prevalence of anxiety, depression and overall distress amongst radiotherapy patients, as measured by the HADS, was 15%, 5.7% and 22% respectively. These findings are comparable with studies from the UK that have reported a likely presence of anxiety, depression and distress among cancer patients of between 9-19% [3, 4], 5-9% [3, 4], and 22-23% [5, 6], respectively. Compared with HADS classifications of anxiety and depression, patients’ perceptions of their anxiety and depression levels provided a stronger model of association with preference to be offered professional support. Eliciting and responding to patients’ preference to be offered professional help may offer a more patient-centred (or more preference-sensitive) approach to psychological care. However, this approach would need to be carefully balanced with the prioritisation of limited psychosocial resources and the need
to ensure that those with limited insight into their elevated psychological distress are identified and linked with appropriate services.

**Key finding three**

The domains of patient-centred care that were most frequently endorsed as those in which better care would have greatly improved patients’ well-being were “information and communication about cancer and care” and “emotional and spiritual support”. Almost one-third of radiotherapy patients identified more than one domain of patient-centred care where better care would have greatly improved their well-being. Migrants to Australia (compared with Australian-born respondents) and younger cancer patients (compared with older cancer patients) had higher odds of identifying multiple domains that required improvement.

**D.1.2 Methodological factors affecting interpretation of results**

**Representativeness of the sample**

Recruitment limited to public treatment centres in metropolitan New South Wales

This thesis examined perceptions of patient-centred care amongst radiotherapy patients with heterogeneous cancer diagnoses. Participants were recruited from metropolitan cancer treatment centres attached to public hospitals in NSW. Cancer treatment centres provide a practical location for identifying radiation oncology outpatients and initiating assessments of their preferences for and experiences of cancer care [7, 8]. In Australia, radiotherapy has, until recently, only been offered in metropolitan centres [9, 10]. As a result, metropolitan facilities have typically treated a wide range of patients – public and private, and those from urban, regional and rural locations [10, 11]. In order to address access issues, regional cancer care centres and private hospitals are increasingly offering radiotherapy treatment [9]. Given that recruitment was conducted in public metropolitan hospital radiotherapy treatment
centres, the results may not be generalisable to regional or private radiotherapy settings. Therefore, there remains a need to investigate patient-centred care amongst radiotherapy patients in regional settings and in private radiotherapy facilities, as experiences of care may differ for cancer patients who live and receive care in urban and regional settings [12-16], and who receive cancer care in public settings, private settings or both [17, 18].

**Sampling bias**

In 2010, three treatment centres involved in this study had 3 linear accelerators, and one had 5 linear accelerators [9]. The NSW Health planning parameters estimate a throughput of 331 new treatment courses per linear accelerator per year (i.e. approximately 28 new treatment courses per machine per month) [9]. During 2010, recruitment days were staggered across the four sites: Site 1 (February-March, May, August-September); Site 2 (June-July, September-October); Site 3 (October, December); and Site 4 (December). It would be expected that this would produce a pool of approximately 1000 potentially eligible patients during the study period. As participants were approached on the basis of research assistant and touch screen computer availability, there may have been a sampling bias introduced to this study sample. A total of 650 patients were assessed for eligibility during the study period, indicating reasonable coverage of the patients receiving treatment during the study period. Information about patients who were not assessed for study eligibility was not collected, and so judgements about whether these patients differed in any systematic way from those who were screened for eligibility cannot be made.

**Response bias**

Research assistants were asked to record the gender of consenters and non-consenters on the study recruitment log sheet. Forty-nine percent of consenters were
female, compared with 42% of non-consenters; however, this difference was not significant ($p = 0.2801$). Additionally, consent rates were comparable to or higher than consent rates obtained in other survey studies assessing cancer patients’ preferences for and experiences of care [19, 20]. However, as detailed disease and demographic characteristics of non-consenters were not obtained, we are unable to ascertain response bias beyond the gender information collected. There were also some incomplete surveys due to patients being called in to their appointments before finishing the survey. Alternative approaches to consent-seeking (such as requesting that patients arrive earlier than usual for treatment to ensure ample opportunity for informed consent process and survey completion) may have increased survey consent and completion rates amongst eligible patients [21].

Limited to respondents with adequate English for survey completion

Eligibility for study participation was restricted to respondents with adequate English-language proficiency for survey completion. This is a common limitation of research conducted with cancer patients in predominantly English-speaking countries [22]. Making surveys available in multiple languages and involving multilingual research assistants may have increased the representativeness of study samples and allowed for identification of the types of issues that may be faced by minority groups [23]. It is also possible that the associations reported in Paper Five (i.e. compared with Australian-born respondents, migrants to Australia were more likely to identify multiple domains where better care would have improved their well-being) and Paper One (i.e. Asian migrants to Australia had lower odds of answering life expectancy survey questions) may have been amplified if the survey had been available in multiple languages.
**Cross-sectional survey design**

This thesis examined disease and demographic variables associated with:

- Paper One: Being willing to answer survey questions about life expectancy
- Paper Two: Patient-centred life expectancy disclosure
- Paper Three: Having a likely presence of i) anxiety, ii) depression and iii) general psychological distress
- Paper Four: Having a preference to be offered support for anxiety or depression, and a hypothetical willingness to accept specific types of psychological support
- Paper Five: A perception that better patient-centred care would improve well-being in i) specific domains and ii) multiple domains.

The cross-sectional study design used does not allow causal relationships to be identified. Additionally, in some of these studies only large associations could be detected due to the small sample sizes for some binary outcomes, leading to a lack of power. Future research should examine these associations using appropriately designed (and appropriately powered) longitudinal research to allow better capture of predictive associations. These studies could also explore how these associations may vary over time, i.e. before treatment, during radiotherapy and after treatment [24, 25].

**Data collection using a touch screen computer questionnaire**

Both qualitative and quantitative methods can be used to build an understanding of patients’ preferences for and experiences of cancer care [26-28]. Qualitative methods, such as focus groups and structured interviews, are frequently used in assessing patient views of cancer care. These methods provide opportunities for researchers to gather detailed information and clarify research questions with participants [29]. However, rigorous qualitative methods usually require transcription of interviews or
focus group discussions prior to analysis, often adding to research personnel costs [30, 31]. Whilst qualitative methods generally provide rich data, they typically only provide information about the views and experiences of small numbers of purposively sampled participants [32]. There may also be demand characteristics and social desirability biases associated with face-to-face qualitative research methods [33], with patients less likely to report certain details about sensitive topics in person during interviews, compared with self-administered data collection modalities [34, 35].

In contrast, quantitative methods use predetermined response options, making this method useful for capturing the prevalence of particular experiences [36]. Quantitative data collection typically aims to involve large, representative samples of patients. This enables the application of statistical tests to the data to determine if there are differences in characteristics of people who report particular preferences for and experiences of care [37]. To maximise generalisability of research findings and minimise social desirability biases, a quantitative method was chosen for this body of work [33].

Whilst patient questionnaires are a common method of quantitative data collection [38], the mode of questionnaire administration (e.g. paper-and-pencil or electronic methods) varies [33]. Structured, self-administered paper-and-pencil questionnaires are commonly used for quantitative data collection. However, completed paper-and-pencil questionnaires require time-consuming manual scoring and data entry or, alternatively, electronic scanning [39]. There is limited capacity in paper-and-pencil questionnaires to tailor questions based on participants’ previous responses. Electronic data collection methods, including touch screen computer questionnaires, enable automatic survey branching, which eliminates the need for patients to self-navigate through potentially complex survey skip patterns [40]. Also, automatic generation of data from the touch
screen computer survey eliminates data entry requirements [33]. In clinical settings, data collection using touch screen computer questionnaires has a number of practical advantages over paper-and-pencil survey administration, including fewer missing values [39, 41, 42]. Additionally, scores on standardised instruments (such as the HADS) are comparable when administered by touch screen computer and paper-and-pencil questionnaires [43].

Touch screen computer surveys assessing psychosocial well-being and completed in an oncology waiting room have been found to be acceptable to cancer patients [41, 44, 45]. Although computer literacy varies considerably across age groups [40], touch screen computer surveys have been found to be highly acceptable to cancer patients, irrespective of age or gender [45, 46]. In a United Kingdom (UK) study using quality-of-life measures, 52% of cancer patients indicated that they would prefer touch screen surveys over paper-and-pencil surveys, and 24% indicated that they had no preference for survey mode [44]. These findings suggest that touch screen computers are an acceptable data collection method. Paper Three reported high levels of acceptability for the touch screen survey. However, some participants requested more assistance than others with survey administration (either from the research assistant or an accompanying person), thus possibly impacting on the quality of data and the validity of results [33].

**Self-reported medical and socio-demographic variables**

Assessing patients’ medical and socio-demographic characteristics by self-report is less expensive than obtaining this information through medical record review or other data-linkage processes [47-49]. Assessment of medical variables via patient self-report may have resulted in some degree of inaccuracy in the information obtained [50]. However, validation of self-reported cancer history against medical records and cancer
registry data has been associated with high sensitivity [51] and accuracy [52]. Patient self-report of medical variables was considered to be a cost-effective approach to information gathering for this series of studies.

D.2 Patient-centred life expectancy disclosure

In Western countries, a consistent finding in studies assessing cancer patients’ communication preferences and experiences is that some of the most prevalent unmet needs or concerns relate to information about cancer diagnosis, treatment and prognosis [53-57]. For this reason, prognosis communication preferences and experiences were explored in Paper Two [58]. A patient-centred approach emphasises the importance of tailoring information and adapting communication to the needs, values and preferences of each patient [59-63]. For this reason, we aimed to explore the extent to which patients’ experiences of and preferences for prognosis discussion were aligned.

The concept of patient-centred care was applied to the consent-gaining process for completion of survey questions related to life expectancy (Paper One). Those who had consented to participate in the larger survey were able to “opt out” of the questions on life expectancy if they wished to. Paper One aimed to determine the proportion of cancer patients willing to answer survey questions regarding life expectancy, and establish disease and demographic predictors of “opting in” versus “opting out”.

Paper Two reported results from the subset of participants who completed the life expectancy questions. It aimed to examine cancer patients’ preferences for life expectancy information disclosure, and to explore the level of agreement between cancer patients’ preferences for and experiences of the disclosure of life expectancy information. Paper Two also aimed to identify subgroups of patients who were more
likely to have life expectancy information disclosed to them in a manner consistent with their preferences.

D.2.1 Key findings – Paper One

Survey questions about life expectancy appeared to be acceptable to the majority of radiotherapy patients. However, acceptability was lower amongst some respondent groups. Overall, 70% (n = 327) of the 469 total respondents (and 50% of eligible patients approached during this study) indicated that they were willing to answer survey questions about life expectancy. Providing the option of skipping or completing life expectancy questions embedded within a larger survey appears to be an acceptable approach to research in this potentially sensitive area. Acceptability of these questions seemed to be lower amongst respondents who were female (compared with males), older adults (compared with younger adults), patients diagnosed with cancers other than prostate cancer, and patients born in Asia (compared with Australian-born respondents).

D.2.2 Key findings – Paper Two

A subsample of 208 respondents was asked about their preferences for and experiences of life expectancy disclosure. The majority (86%) had a preference for self-determined disclosure decision-making, and 66% of respondents reported a self-determined disclosure decision-making experience. However, there was poor agreement between radiotherapy patients’ life expectancy disclosure preferences and experiences (self-determined versus other-determined). Findings suggest a need for improved patient-centred prognosis disclosure, particularly for males and for patients closer to the point of diagnosis. These findings make an important contribution to the patient-centred care literature, particularly with regard to prognosis disclosure, and may
help to guide clinicians in developing communication styles that are more responsive to patient preferences.

D.2.3 **Strengths of these studies**

*A representative sample of radiotherapy patients*

Most research into patient preferences for life expectancy communication has focused on early-stage cancer patients [64]. Research into patients’ experiences of life expectancy disclosure is largely based on samples of advanced-cancer patients [65], patients diagnosed with a range of life-limiting diseases [66, 67], and breast cancer or melanoma patients [68, 69]. Papers One and Two explored the life expectancy disclosure preferences and experiences of a heterogeneous sample that included both early- and advanced-stage cancer patients. This allowed the identification of subgroups that were less likely to receive care in accordance with their preferences (Paper Two).

*Addressing ethical issues of research into potentially sensitive topics*

In Australia, medical research is guided by the Western neo-liberal ethical principles of autonomy, beneficence, non-maleficence, justice and respect, all of which are endorsed by the National Statement on Ethical Conduct in Human Research (2007) [70]. At times, there is a need to balance ethical principles which may be in conflict, such as autonomy and beneficence. For research on potentially sensitive topics such as life expectancy, these issues may be particularly pertinent. Considering that a substantial minority of patients may not want to know, or reflect on, their prognosis [66, 69, 71, 72], there is a need to ensure that the ethical principles of beneficence and non-maleficence are recognised in research on this topic.

Attempts to increase the representativeness of life expectancy disclosure research through random sampling or recruitment of consecutive patients may be hampered by
professional and familial gate-keeping, which is typically guided by beneficence and non-maleficence [73]. This poses dilemmas related to both ethics and research methodology. Professional and familial gate-keeping can restrict patient autonomy and also limit the external validity of research findings [74]. Papers One and Two address these issues. Firstly, by recruiting patients from general radiotherapy treatment centre waiting rooms, rather than from specific outpatient clinic waiting rooms (that may be linked to particular doctors on particular days), a broad cross-section of patients with different primary radiation oncologists were identified. Secondly, providing survey respondents with an opportunity to opt out of answering the life expectancy questions embedded within the larger survey was thought to provide a balance between the ethical principles of beneficence, non-maleficence and autonomy [75]. The use of this methodology led to an acceptable consent rate, whilst also providing an indication of the disease and demographic characteristics of survey respondents who are less likely to answer survey questions about life expectancy. Similar methodology has been adapted and tested within a study that also explored potentially sensitive topics, using mailed survey recruitment [74].

Assessment of patient self-reported life expectancy disclosure experiences

There are a range of different methods of assessing life expectancy disclosure in clinical settings [76]. These methods include patient self-report, carer self-report [77, 78], clinician self-report, observation, medical records, diaries and unannounced standardised patients (i.e. actors covertly presenting as patients) [79]. The reliability, validity and acceptability of these methodologies needs to be considered to determine whether the results of an assessment are credible and able to detect changes in life expectancy disclosure practices [76]. The perceptions and understanding that patients take from their cancer consultations are important indicators of the extent to which life
expectancy disclosure experiences are patient-centred [80]. Australian research has identified that many women with breast cancer do not understand the jargon clinicians use when discussing prognosis with them, highlighting the need for clinicians to assess patient understanding of the information provided to them [81]. Patient-centred life expectancy disclosure requires the provision of information which not only addresses individuals’ information needs, but is also understandable [80]. Patient comprehension of life expectancy information is crucial when considering the legal imperative to allow patients to make informed treatment decisions about their healthcare [66].

Surveys of patient perceptions have been criticised as being influenced by recall and reporting biases [79]. Patients’ preferences and personality may also impact on responses; for instance, coping strategies or cognitive filtration processes may influence patient self-report, manifesting in patient denial [82, 83], false optimism [84, 85], or misunderstanding [86-90]. Future research could supplement patient self-reported experiences of life expectancy disclosure with observational methods (such as audiotaping of consultations) to assess consultation content [85, 91-93]. Combining these methodologies could provide useful insight into the reasons for poor agreement between patients’ preferences for and experiences of life expectancy discussions. This may provide guidance on whether interventions should target a) improving patient understanding, b) improving clinician communication competency in initiating life expectancy discussions in a patient-centred way, or c) both of these.

Assessment of concordance between preferences and experiences

There is one published study that assessed concordance between cancer patients’ preferences for and perceived experiences of life expectancy disclosure in the United States of America (USA) [94]. The generalisability of these findings is limited by the following factors: patient recruitment from the American Cancer Society mailing list
from the Michigan area of the USA; a response rate of approximately 24%; and an overrepresentation of some disease and demographic subgroups (i.e. females and breast cancer patients) [94]. Paper Two is the first study to focus on a heterogeneous group of cancer patients recruited from radiation oncology treatment centres, and to assess concordance between patients’ preferences for and perceived experiences of life expectancy disclosure. An investigator-derived algorithm was used to assess whether patients’ preferences and perceived experiences were aligned (i.e. patient-centred). Paper Two indicates that the observed agreement between preferences and perceived experiences was only 60% and Cohen’s \( \kappa \) was -0.04, indicating that agreement was very poor. These findings suggest that there is room to improve the patient-centredness of life expectancy communication.

D.2.4 Limitations of these studies

**Response bias to life expectancy survey section**

Survey respondents who opted out of the life expectancy section were possibly more likely to have a preference for other-determined disclosure. This may have led to an overestimation of the true proportion of patients’ preference for self-determined disclosure. There is a need to broaden our understanding of what predicts patients’ preferences for life expectancy disclosure, in order to support clinical decision-making in this area.

**Influence of radiotherapy setting on responses**

Given that 99% of cancer patients have identified that oncologists are primarily responsible for their care [66], Paper Three examined patients’ experiences of life expectancy discussions with their oncologists. Although respondents were asked a generic question about whether they had discussed and wanted to discuss life expectancy with their “cancer doctor”, the survey setting may have influenced patients
to only consider communications with their radiation oncologists, rather than other specialists involved in their cancer care.

D.3 Anxiety, depression, psychological distress and patients’ support preferences

It has previously been identified that about 30% of cancer patients experience heightened levels of psychological morbidity as a consequence of cancer and its treatment [95], and that a large proportion of those with clinically significant distress do not receive appropriate treatment for this distress [96]. This situation may be linked to poor identification and referral of cancer patients’ psychosocial concerns [97-100]. It may also be linked to cancer patients’ preferences for and willingness to accept the psychosocial support services to which they are referred [96, 101-105]. Untreated depression is associated with three times the odds of non-adherence to recommended treatments [106]. Links between untreated anxiety and non-adherence may also exist [106, 107]. Non-adherence to recommended radiotherapy courses has been associated with poor treatment outcomes for cancer patients [108-110]. Untreated depression and anxiety may also negatively impact on patients’ quality of life and adjustment to treatment [3, 111].

Papers Three and Four present the psychological distress levels and treatment preferences of radiotherapy outpatients. Paper Three aimed to establish in a radiation oncology patient population: 1) the likely presence of a) anxiety, b) depression and c) overall distress using the HADS; and 2) factors associated with a likely presence of a) anxiety, b) depression and c) overall distress. The acceptability of the touch screen computer survey conducted in radiotherapy treatment waiting rooms was also assessed. Paper Four firstly aimed to assess agreement between reported anxiety and depression levels of cancer patients using a) single self-report items and b) the HADS.
Secondly, Paper Four explored whether anxiety and depression assessment by a) single self-report items or b) the HADS was more strongly associated with a preference to be offered professional assistance. The proportion of patients indicating that they would accept (or were currently using) professional support if they were experiencing anxiety or depression was also examined.

D.3.1 Key findings – Paper Three
A total of 454 respondents completed the HADS section of the touch screen survey. Compared with non-clinical population norms from the UK [112], HADS-classified anxiety, depression and overall psychological distress levels were elevated amongst cancer patients receiving radiotherapy. The odds of a likely presence of anxiety, depression and distress were found to differ by cancer type. Compared with a breast cancer reference group, prostate cancer patients had lower odds of anxiety and overall distress. Compared with a breast cancer reference group, patients with other common cancers (e.g. non-Hodgkin’s lymphoma, brain cancer, colorectal cancer, head and neck cancer, and lung cancer) had higher odds of depression. Touch screen computer surveys were a feasible way of collecting information about psychological distress, and this approach was found to be acceptable to patients, with high consent rates and patient self-reported acceptability. Given that 57% of respondents would be willing to complete a touchscreen computer survey on at least every second visit to the treatment centre, and that patients frequently attend the treatment centre during radiotherapy, a window of opportunity exists for intervention in this setting.

D.3.2 Key findings – Paper Four
A total of 304 respondents completed the HADS and reported on their perceived levels of anxiety and depression. When using single items to assess patients' perceived levels (i.e. none, mild, moderate and severe) of anxiety and of depression, 50% of
radiotherapy patients perceived that they were currently experiencing mild-to-severe levels of anxiety, and 31% mild-to-severe depression. These proportions are larger than those indicated by HADS classification levels in the same sample (i.e. 29% mild-to-severe anxiety and 17% mild-to-severe depression). Overall, 22% of respondents indicated a preference to be offered professional help. There was moderate agreement between the HADS and single-item responses for categorisation of anxiety (93% observed proportion of agreement) and depression (95% observed proportion of agreement; both weighted ω = 0.5). Patients’ self-perceived distress levels provided a marginally stronger model of association with a desire to be offered professional support than HADS classifications. Of a subsample of 193 respondents, 89% indicated that if they were experiencing anxiety or depression, they would accept (or were currently using) professional support. The majority indicated they would probably accept (or were currently using) psychological support from their cancer doctors (81%) and general practitioners (71%).

### D.3.4 Strengths of these studies

_A representative sample of radiotherapy outpatients_

The likely prevalence and factors associated with anxiety, depression and general psychological distress has been widely investigated with cancer patients. However, of the few studies that have focused on patients during radiotherapy, most have been limited by the recruitment of small samples [3, 111] and a focus on the more common cancer types [113]. Collecting information from a large sample of cancer patients attending routine radiotherapy appointments enabled this study to recruit cancer patients with different cancer sites, disease stages and treatment goals, making this study more representative of the radiotherapy setting. An additional strength of these studies is the high survey consent and completion rates obtained, with 86% to 87% of
eligible patients consenting and 69% to 79% providing complete survey responses across the three papers.

**A reliable and valid measurement tool**

The HADS was used to assess levels of anxiety, depression and general psychological distress. This scale has been widely used for clinical and research purposes [114] and has demonstrated reliability and validity in oncology populations [115]. The HADS factor structure and threshold scores recommendations have been questioned [116-118]. However, a recent review recommended the HADS as the optimal outcome measure for assessing anxiety, affective disorders and general distress in psychological intervention trials in oncology settings [119]. The HADS scores have been found to be comparable when administered by touch screen computer and paper-and-pencil surveys in a cancer patient population [43].

**Assessment of patients’ perceived levels of anxiety and depression**

This study reports on cancer patients’ perceived levels of anxiety and depression. Prior to this study, the only published study assessing single-item assessment of anxiety and depression in cancer outpatients required a yes or no response from the patient when a nurse directly asked, “Are you anxious?” and “Are you depressed?” [120]. A meta-analysis of ultra-short screening measures for depression in cancer settings (with yes/no responses) validated against gold standard semi-structured diagnostic interviews suggested that single items were not sensitive to confirming depression but were specific (i.e. able to exclude non-cases) [121]. Skoogh and colleagues [122] found that adding an “I don’t know” response to single-item questions about depression increased sensitivity. Multiple response categories to assess perceived severity or level of anxiety and depression were used in this study [123].
D.3.5 Limitations of these studies

Alignment of HADS and perceived anxiety and depression categories

Although patients’ self-perceived anxiety and depression categories were compared with HADS categories, category descriptions varied slightly between the measures used. We compared a patient rating of “none” with a HADS rating of “normal” for both anxiety and depression. Given that the HADS categorisation of “normal anxiety” and “normal depression” may include some level of anxiety and depression, respondents may have perceived that they were suffering “mild” anxiety or depression, whilst scoring in the “normal” category on HADS.

Hypothetical indication of service uptake

Patients were asked to indicate their likely acceptance of service (in the hypothetical event that they were anxious or depressed) and current service use. Linkage between referrals made and uptake of those referrals was not assessed. Although understanding patients’ hypothetical preferences is important, these preferences may not align with actual service uptake behaviour should patients experience anxiety and/or depression [124]. Additionally, the assessed styles of support may not reflect the services and referrals available within and external to all cancer treatment centres.

D.4 Radiation oncology outpatients’ perceptions of patient-centred care

Provision of patient-centred care may contribute to improvements in patients’ physical, mental and social well-being [125-130]. Paper Five aimed to examine the proportion and characteristics of radiation therapy patients who indicated that their well-being could have been improved by better cancer care. This was assessed using an investigator-derived measure. This measure assessed patients’ perceptions across eight domains of patient-centred care that were identified on the basis of a synthesis of
past literature reporting on cancer outpatients’ experiences of care [19, 131-135].
Characteristics associated with patients’ perceptions that better care across individual
and multiple domains of patient-centred care would have improved their well-being
were also explored.

The domains of patient-centred care assessed in Paper Five were:

i. Management of physical symptoms (e.g. pain, sleeplessness, other side-effects
and symptoms)

ii. Information and communication about cancer and care (e.g. clear and
consistent information about your diagnosis, test results, treatment, taking
medications, food you should be eating and exercise you can do safely)

iii. Emotional or spiritual support (i.e. services or support to help you cope with the
impact of cancer on your life, doubts/worries, feelings of anxiety or sadness,
and changes to your body image)

iv. Services, information and support for friends and family (e.g. helping them to
cope with the impact of cancer, or providing opportunities for them to be
involved in care)

v. Staff approachability and respect for the patient (e.g. staff who are easy to
contact and up-to-date with the patient’s medical history and give the patient
opportunities to ask questions and be involved in treatment decisions)

vi. Access to care when required (e.g. not having to wait too long to get
appointments and having treatment and medical advice available when needed)

vii. Services or support to cope with changes to relationships (e.g. knowing what
changes to expect, and having some strategies to reduce the impact of cancer
on your work, usual social activities, friendships and sexual relationships)
viii. Services or advice to assist with practical concerns (e.g. accessing financial support, transport to treatment, home help services or other support needed to manage practical issues).

D.4.1 Key findings – Paper Five

Paper Five reported on 344 radiation oncology outpatients’ perceptions of patient-centred care. Almost one-third of the respondents identified more than one domain where better care would have greatly improved their well-being. Younger patients and migrants to Australia had higher odds of identifying multiple domains of patient-centred care. When separately assessing disease and socio-demographic associations with each of the eight domains of patient-centred care, Australian-born patients had lower odds of endorsing each of the patient-centred care domains. Older adults had lower odds of endorsing all domains except two (i.e. physical symptom management, and staff approachability and respect for the patient). Patients likely to have depression had higher odds of endorsing domains of information and communication, emotional and spiritual support, and support with changes to relationships. Overall, the top two domains of patient-centred care that radiotherapy patients perceived their well-being would have been greatly improved by better care were “Information and communication about cancer and care” and “Emotional and spiritual support”, both of which were endorsed by more than one-fifth of respondents.

D.4.2 Strengths of this study

A representative sample of radiotherapy patients

Paper Five reports higher survey consent and completion rates than past Australian investigations of cancer outpatients’ experiences of care [19] and is the first large Australian study to focus specifically on radiotherapy outpatients [136]. The inclusion of radiotherapy patients from multiple treatment centres in the Australian state of NSW,
with a range of disease and socio-demographic characteristics, provided access to a representative sample of patients receiving radiotherapy in 2010 (when treatment was primarily delivered by treatment centres attached to large metropolitan public hospitals). This enabled an analysis of whether particular groups were less likely to receive (or perceive) patient-centred care.

**A novel approach to assessing perceptions of patient-centred care**

Well-being is relevant to patient-centred care, given that both concepts are aligned with a holistic view of physical and mental health [137-141]. Past research has identified associations between the provision of patient-centred care and patient well-being [125, 126], including improved quality of life [127-130] and reduced anxiety and depression [128-130, 142]. Patient well-being can also be influenced more indirectly through the provision of patient-centred care, such as through the development of a trusting patient-clinician relationship [143, 144]. To the best of our knowledge, this was the first study to ask cancer patients undergoing radiotherapy about their perceptions of whether better care in different patient-centred domains would have improved their well-being [145].

Previous research has assessed patients’ perceptions of patient-centred care through satisfaction and experience surveys. This work has reported that up to 50% of cancer outpatients are dissatisfied with the level of information provided about physical symptom management, emotional support, involvement of family, and some aspects of access to care [19, 132, 133]. Patient satisfaction surveys have been criticised for failing to consider patients’ expectations within patients’ judgements about their care [132, 146]. Additionally, satisfaction surveys do not indicate where quality improvement initiatives should be directed or prioritised to maximise improvements in patients’ satisfaction with care [133]. The approach to assessing outpatients’ perceptions of care
detailed in Paper Five required patients’ appraisal of whether their well-being would have been greatly improved by better care across each of the eight patient-centred domains [147]. Thus, patients’ expectations of their optimal well-being was used to provide an indication of the relative impact that better care in each domain would have made to their well-being [148]. Consequently, the findings indicate not only which patient-centred domains are in need of improvement, but also the personal relevance of this improvement to patients’ perceived well-being.

*A measure based on widely endorsed conceptual frameworks and guidelines*

The domains of patient-centred care assessed in Paper Five drew largely on the conceptual framework of patient-centred care first described by Gerteis and colleagues [131], which has been applied in Picker Institute surveys of patient experience internationally [19, 131, 132] and endorsed in part by the Institute of Medicine in the USA [149]. Additional refinement of the domains assessed drew on recent patient-centred quality indicators developed from patient-centred oncology clinical practice guidelines [133, 134]. These domains of patient-centred care are relevant both to radiotherapy [8, 136, 150-153] and to broader outpatient cancer care experiences [19, 80, 128, 133, 154-160].

**D.4.3 Limitations of this study**

*Limited assessment of patients’ perceptions of spiritual support*

In Paper Five (and in this thesis), assessment of patients’ perceptions of spiritual support was limited to a combined “emotional and spiritual support” domain of patient-centred care. This approach was taken because existing definitions of spirituality and spiritual wellbeing overlap with conceptualisations of emotional wellbeing, making it challenging to separate these concepts [161-163]. Spirituality has been broadly defined as a sense of awareness, meaning and connectedness, which characterises an
individual’s perspective on the world [164-167]. Spirituality is influenced by personal and cultural factors, and may be closely linked with structured religious belief systems [168, 169]. Given the highly personalised nature of spirituality [168], and that being faced with a cancer diagnosis, cancer suffering or cancer death may challenge existing spiritual perspectives [166], this construct has relevance to patient-centred cancer care [166]. Although more than half of all US oncology outpatients would like health care providers to ask about their spiritual standpoint [170, 171], a recent Cochrane Review indicates that evidence of the influence of spiritual or religious interventions on the wellbeing of patients with a terminal illness is inconclusive [172]. Current Australian guidelines for the provision of psychosocial care indicate that terminal cancer patients should be asked about whether faith, religion, or spirituality is important to their experience of illness and treatment [173]. The impact of assessing cancer patients’ spiritual standpoints could be explored in more depth, particularly in Australian oncology outpatient settings [172, 174].

**Requirement for further psychometric evaluation of the patient-centred care measure**

There are few psychometrically robust and comprehensive measures of patients’ perceptions of patient-centred care, suitable for use with heterogeneous cancer populations [157, 175]. Therefore, an investigator-derived measure was used in the current study. As described earlier, this measure enabled assessment of the patients’ perceptions of whether improvement in specific patient-centred domains would have improved their well-being. Although the investigator-derived patient-centred care measure used in Paper Five appeared to have good face and internal reliability, a more detailed psychometric assessment of the properties of the measure is required. It is important that patient-reported measures not only reliably and accurately assess the constructs of interest, but that they are also sensitive enough to detect changes in the
construct over time [176]. Therefore, it is important that future work examines the sensitivity of the measure used in the current study, as well as the sensitivity of other measures of patient-centred care. Establishment of sensitivity is particularly important where measures are used to examine change in response to an intervention.

D.5 Conclusions and recommendations for future research

In Australian radiotherapy settings, there has been limited research that has aimed to assess and improve cancer patients’ experiences of care [152, 177]. The work presented in this thesis provides some important descriptive insights into cancer patients’ preferences for and experiences of care during radiotherapy. Key conclusions from this body of work include the need to a) improve concordance between patients’ preferences for and experience of the disclosure of life expectancy information, b) consider how patients’ perceptions of psychological distress can and should be factored into psychosocial referrals, and c) improve provision of patient-centred cancer care, particularly for younger patients and those born outside Australia.

Extending on these findings, a series of intervention studies that aim to reduce the psychosocial burden of cancer and improve quality of care are proposed. During radiotherapy, patients typically have repeated interactions with the healthcare system and healthcare providers [178]. Routine radiotherapy appointments provide an opportune time and setting to intervene with cancer patients with the aim to improve experiences of care, well-being and other psychosocial outcomes [150, 179]. There is also potential to test the feasibility and effectiveness of interventions which encompass expanded roles of radiotherapists and radiation oncology nursing staff in the provision of supportive cancer care [151, 178, 180, 181]. Some recommendations for future research are proposed below.
D.5.1 Assessing health impacts of life expectancy communication interventions

Papers One and Two reported descriptive findings related to the patient-centredness of life expectancy disclosure. There is a need for interventions aimed at shifting life expectancy disclosure practice into alignment with the patient-centred approach recommended by consensus guidelines. Additionally, to support these consensus recommendations [2], high-level evidence of the impact of patient-centred life expectancy disclosure on patient outcomes is needed [182]. Future research should examine whether interventions targeting health professional communication skills (e.g. training) and patient understanding (e.g. question prompt lists and increased family involvement) can positively impact on a) patient-centredness of life expectancy disclosure, b) mental health outcomes of patients, and c) mental health outcomes of clinicians.

The potentially sensitive nature of this research topic may result in barriers to conducting intervention trials, such as poor intervention protocol adherence. To monitor intervention fidelity, patient self-reported outcomes should be combined with observational methods (such as audiotaping of consultations) [85, 91-93]. Combining these methods may provide an indication of the reasons for non-concordance between doctors and patients regarding life expectancy communications.

D.5.2 Examining the role of preference effects in psycho-oncology intervention studies

The randomised controlled trial (RCT) is considered to be the gold standard research design for examining whether an intervention can produce clinically meaningful changes in outcomes of interest. The process of random allocation to groups removes between-group differences by distributing known and unknown confounding factors between groups [183, 184]. However, outcomes of RCTs may be influenced by “preference effects” that depend on whether participants are randomised to their
preferred treatment arm. This is particularly the case in psycho-oncology intervention trials where participants cannot be blinded to treatment category, and where (as Paper Four reports) desire for support and preferences for modes and locations of support vary. If RCT participants are not allocated to their preferred treatment categories, motivation, adherence and expectations may be lowered [183], potentially impacting on intervention integrity and trial outcomes [185]. Factoring patients’ preferences for group allocation into research designs has been found to improve intervention adherence in studies of health education [186] and psychology [185].

Marvin Zelen [187] was the first to propose an alternative approach to the traditional RCT, as an attempt to reduce some of the aforementioned participant preference influences on trial recruitment rates. In a Zelen post-randomised consent RCT, a pre-identified patient cohort (who are scheduled to receive standard care) are randomly allocated to an experimental treatment arm, prior to their consent for trial participation being obtained. Following randomisation, consent is sought from individuals allocated to the experimental arm only (single consent design; [187]), or to both experimental and standard care arms (double consent design; [188]). Patients can then ‘cross-over’, or opt-out of the experimental arm and back into the standard care arm (and vice versa), intervention effects are analysed using intention-to-treat analysis (i.e. based on original trial group allocation). Cross-over effects are a potential limitation of these designs, as this may dilute intervention effects, leading to a loss of study power [189, 190]. There are also considerable ethical issues associated with randomisation prior to obtaining consent from potential participants [189].

Brewin and Bradley [191] went on to address the ethical limitations of the Zelen RCT, proposing partially randomised preference trials (PRPTs, also referred to as 2-stage randomised designs) as an alternative methodological approach to overcome
preference effects associated with unblinded RCTs. Participants who either express no preferences for any treatment condition, or who consent to randomisation, are randomised, whilst other participants are able to enrol in the treatment arm that corresponds with their preference. Comparisons across these four study groups (Randomised to treatment, Randomised to control, Self-selected to treatment, and Self-selected to control) allows assessment of treatment effects and self-selection bias simultaneously. It is thought that this may better reflect clinical referral and decision-making processes than using the RCT study design [184]. It is also a more patient-centred approach to research as it returns autonomy and control to participants [183, 192]. A disadvantage of this study design is that uncontrolled factors in the self-selected trial arms may lead to reduced ability to determine which treatment arm is the most effective, irrespective of motivational factors [184]. There are also likely to be additional sample size requirements of this design in order to ensure the trials are adequately powered [192, 193].

There is great potential for the application of “preference trials” in psycho-oncology. These trial designs represent a shift from RCT efficacy testing into effectiveness testing. A PRPT design could be applied to examine the role of preferences on intervention adherence and on psychological distress outcomes for cancer patients. This research design is arguably a more patient-centred approach to research, and may provide insight into how preferences may influence service uptake and psychosocial outcomes.

D.5.3 Perspectives on patient-centred care in ethnically diverse communities
As of 30 June 2011, 27% of Australian residents were born overseas, and 2% of Australians aged 5 and over did not speak English at all [194]. The majority of psycho-oncology research in Australia is conducted in English, meaning that Culturally and
Linguistically Diverse (CALD) cancer patients are frequently excluded or under-represented in research findings. Paper Five reported that, compared with cancer patients born in Australia, those who were born overseas were more likely to identify multiple domains where better patient-centred care could have improved their well-being. There is a need for further exploration of perceptions of patient-centred care amongst CALD cancer patients in Australia. There is also a need to examine how patient-centred care could better meet the needs of an ethnically diverse population.

Cultural competence in healthcare is described as having attitudes, knowledge and understanding of the cultural diversity of individuals, and having the skills to factor these into the clinical setting [195]. Patient-centred care and cultural competence both require respect for and responsiveness to patients’ unique cultural values and personal preferences [196, 197].

To date, there has been limited work assessing the psychosocial well-being of CALD cancer patients in Australia [22, 198, 199]. Recently, Butow and colleagues have identified poorer quality of life in recently-diagnosed CALD immigrant cancer patients, compared with Anglo-Australians [23, 200]. However, this study recruited patients through population-based cancer registries. There is a need for studies that recruit from treatment centres, where there are resources (e.g. interpreters) and opportunities to intervene [201]. A similar study has now been funded for recruitment through oncology clinics [202]. There is a need to move into intervention studies that focus on improving the provision of patient-centred care for migrant patients. Drawing on an expanded role of radiotherapists and radiation oncology nursing staff may be an appropriate next step [152, 181, 203-206].

In summary, this thesis indicates several areas in which further investigation of radiation oncology outpatients’ perceptions of cancer care is warranted. Whilst
descriptive studies will be valuable in confirming the current findings, methodologically rigorous intervention trials similar to those mentioned above will help to further our understanding of how important aspects of patient-centred care can be improved for radiotherapy patients.
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266


270


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Patient-centred cancer care: a road less travelled

An investigation in Australian radiotherapy settings

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APPENDICES
Table of contents

APPENDIX 1: PAPER ONE ........................................................................................................ 4
Appendix 1.1: Published paper .......................................................................................... 5
Appendix 1.2: Statements of contribution from co-authors .............................................. 13
Appendix 1.3: Copyright Clearance Licence Agreement .................................................... 17

APPENDIX 2: PAPER TWO ................................................................................................. 22
Appendix 2.1: Published paper .......................................................................................... 23
Appendix 2.2: Statements of contribution from co-authors .............................................. 33
Appendix 2.3: Copyright Clearance Licence Agreement .................................................... 37

APPENDIX 3: PAPER THREE ............................................................................................. 42
Appendix 3.1: Published paper .......................................................................................... 43
Appendix 3.2: Statements of contribution from co-authors .............................................. 53
Appendix 3.3: Copyright Clearance Licence Agreement .................................................... 56

APPENDIX 4: PAPER FOUR ............................................................................................... 61
Appendix 4.1: Published paper .......................................................................................... 62
Appendix 4.2: Statements of contribution from co-authors .............................................. 70
Appendix 4.3: Copyright Clearance Licence Agreement .................................................... 75

APPENDIX 5: PAPER FIVE ................................................................................................. 85
Appendix 5.1: Published paper .......................................................................................... 86
Appendix 5.2: Statements of contribution from co-authors .............................................. 98
Appendix 5.3: Copyright Clearance Licence Agreement .................................................... 101

APPENDIX 6: ADDITIONAL RELEVANT PUBLICATIONS ............................................ 106
Appendix 6.1: Published conference abstract .................................................................... 107
Appendix 6.2: Published poster listings ............................................................................ 110
Appendix 6.3: Additional publications relevant to thesis .................................................. 127
<table>
<thead>
<tr>
<th>Appendix 6.4: Copyright Clearance Licence Agreements</th>
<th>143</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPENDIX 7: STUDY ETHICS APPROVALS</td>
<td>168</td>
</tr>
<tr>
<td>Appendix 7.1: University of Newcastle Certificates of Human Research Ethics Approval</td>
<td>169</td>
</tr>
<tr>
<td>Appendix 7.2: University of Newcastle Safety Clearance Notification</td>
<td>175</td>
</tr>
<tr>
<td>Appendix 7.3: University of Newcastle Health, Safety &amp; Environment Evaluation Report</td>
<td>177</td>
</tr>
<tr>
<td>Appendix 7.4: South Eastern Sydney and Illawarra Area Health Service Certificates of Human Research Ethics Approval</td>
<td>184</td>
</tr>
<tr>
<td>Appendix 7.5: Cancer Institute NSW Certificates of Human Research Ethics Approval</td>
<td>187</td>
</tr>
<tr>
<td>Appendix 7.6: Hospital site-specific approvals</td>
<td>194</td>
</tr>
<tr>
<td>APPENDIX 8: HOSPITAL ANXIETY AND DEPRESSION SCALE</td>
<td>206</td>
</tr>
<tr>
<td>Appendix 8.1: Hospital Anxiety and Depression Scale permission invoice</td>
<td>207</td>
</tr>
<tr>
<td>APPENDIX 9: STANDARDISED STUDY PROCEDURES AND MATERIALS</td>
<td>208</td>
</tr>
<tr>
<td>Appendix 9.1: Research Assistant Recruitment Manual</td>
<td>209</td>
</tr>
<tr>
<td>Appendix 9.2: Example of touch screen computer survey skip logic</td>
<td>264</td>
</tr>
</tbody>
</table>
Appendix 1: Paper One

Permission to copy and communicate this work, “Cancer patients' willingness to answer survey questions about life expectancy”, has been kindly granted by Springer Science and Business Media.
Appendix 1.1: Published paper
Cancer patients’ willingness to answer survey questions about life expectancy

L. J. Mackenzie · M. L. Carey · R. W. Sanson-Fisher · C. A. D’Este · A. E. Hall

Abstract
Purpose This study aimed to determine the proportion and characteristics of radiation oncology outpatients who were willing to answer questions about their life expectancy.
Methods A cross-sectional patient self-report survey was conducted using touch screen computers in Australian radiation oncology treatment centers. The primary outcome was the respondent’s willingness to complete a survey subsection about life expectancy. Demographic and disease characteristics were also collected, and level of anxiety and depression was assessed using the Hospital Anxiety and Depression Scale.
Results Of the 469 oncology outpatients who completed the survey, 327 (70 %; 95 % CI, 65 %, 74 %) indicated that they were willing to answer questions about life expectancy. Being female (p<0.001), older (p<0.05), born in Asia (p<0.05), and being diagnosed with cancer types other than breast and prostate cancer (p<0.01) were associated with lower odds of answering life expectancy questions.
Conclusions The opportunity to opt-out of survey questions about sensitive issues such as life expectancy is a feasible method for accessing important information about patient preferences while minimizing burden. Further research may be needed to improve acceptability of life expectancy research to some patient groups.

Keywords Cancer · Patient-centered care · Patient preference · Prognosis

Introduction
A cancer diagnosis is often associated with a reduced life expectancy [1]. Therefore oncologists are often faced with the intimidating task of communicating this bad news to patients and their families [2]. Although communication training is provided in medical schools, clinicians have reported feeling inadequately trained in breaking bad news [3]. Variation in individual patient preferences for life expectancy disclosure compounds the complexity of this task for clinicians [3, 4]. Additionally, there is limited evidence about patient disease and demographic characteristics associated with different preferences [5]. Although guidelines based on consensus views have been developed to assist clinicians with the task of life expectancy disclosure [6, 7], it remains critical to build empirical evidence about how different methods of disclosure impact on patient psychosocial outcomes [2].

Although there is a need to build the evidence base regarding prognostic communication [5], ethical concerns about the potential burden of this research have been raised [8]. The development of a patient-centered methodological approach to assessing patients’ preferences for life expectancy disclosure may prove successful for increasing representative research output, while also minimizing the burden of research to patients in accordance with their preferences for involvement. This approach involves embedding a set of optional life expectancy method for accessing important information about patient preferences while minimizing burden. Further research may be needed to improve acceptability of life expectancy research to some patient groups.

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questions within a larger patient experience survey and giving patients the chance to “opt-out” of these questions. It was thought that this may help to minimize patient burden, while also maximizing overall consent rates and representativeness [9]. Importantly, this approach would also allow identification of patient characteristics relating to a willingness to answer these questions, helping to improve our understanding of acceptability of the topic of life expectancy to different cancer patient groups [5].

Aims and hypotheses

This research aimed to determine (1) the proportion of cancer patients willing to answer survey questions about their life expectancy, and (2) examine disease and demographic factors associated with a willingness to answer these questions. We expected that females would be more likely than males to answer life expectancy questions, based on past findings suggesting females want more detailed information about cancer [10]. Based on previous research into cancer patients’ preferences for prognosis communication, it was expected that patients perceiving a shorter survival time would be less likely to complete life expectancy questions than those perceiving a longer survival time [11]. Similarly, we expected that patients reporting that their treatment had curative intent would be more willing to complete the life expectancy questions than those perceiving that their treatment was with palliative intent. It has also been suggested that willingness to participate in research trials may be linked to psychological distress; however, findings are mixed [2, 5, 12]. We expected that respondents born in some Asian and European regions may be less likely to complete life expectancy questions [4, 5], and that younger respondents would be more willing to answer the life expectancy questions [5, 11].

Patients and methods

Ethical standards

All human research was approved by the University of Newcastle HREC and the New South Wales Population and Health Services Research Ethics Committee. Research governance authorization was also sought and obtained from the participating hospitals.

Patients

Cancer outpatients were recruited from four metropolitan radiation therapy treatment centers between February 2010 and December 2010. The four treatment centers were attached to large public teaching hospitals located in high socio-economic status areas of Sydney, Australia. Patients were eligible for inclusion if they were aged 18 years or older; had a cancer diagnosis; were attending radiation therapy treatment as an outpatient, and understood sufficient English to complete the survey. Patients who were attending the clinic for the first time were excluded.

Procedure

A research assistant (RA) approached patients waiting for their radiation therapy treatment appointment. Participants were provided with a written information statement about the study. The RA explained that the survey contained questions about quality of care, coping with cancer, and an optional section about life expectancy. The RA then sought informed consent from eligible patients after indicating that the patient could choose not to complete the section on life expectancy. Once informed consent was obtained, patients completed the survey in the waiting room using a portable touch screen computer. Digivey software (CREOSO Corporation, Phoenix, Arizona) was used to program the survey, which was administered using a Dell Latitude XT2 touch screen computer. The use of touch screen computer surveys in oncology settings has been previously found to be acceptable to cancer patients [13].

Measures

The following modules were embedded within a larger 10–15-min survey:

Outcome measure

The primary outcome was patients’ willingness to complete life expectancy questions. The introduction to this section of the survey read “The following questions ask for your views about your life expectancy. This will provide information that may help to improve services for cancer patients.” Participants were asked to indicate whether or not they were willing to complete questions about their life expectancy by either selecting “I am willing to complete this section of the survey” or “Please skip to the next section of the survey”. If participants initially chose to complete the life expectancy section, but then changed their mind, they could use the “BACK” navigation button on the survey screen to return to the introductory screen for the life expectancy section. This then allowed participants to skip the life expectancy section and any previous responses were deleted.

Explanatory measures

Demographic and disease data on age, gender, diagnosis, country of birth, time since diagnosis, number of outpatient
appointments, number of oncology appointments, and treatment aim were collected via the self-report survey. The Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depression. The HADS contains two seven-item subscales each producing a score between 0 and 21 indicating normal (0–7), mild (8–10), moderate (11–14), or severe (15–21) levels of anxiety, and/or depression [14]. There is evidence that this measure is both reliable and valid in a cancer patient population [15], and produces comparable results when it is administered via paper and pencil or via touch screen computers [16]. Although various thresholds have been used in the literature to identify caseness [17], a subscale score of 11 or more can be indicative of clinically significant levels of anxiety and/or depression [14]. This threshold was used to classify respondents having clinically significant depression or anxiety.

Statistical analysis

The proportion of participants willing to answer survey questions about their life expectancy was estimated with a 95 % confidence interval. Disease and demographic factors hypothesized as being associated with a willingness to answer these questions were examined using univariate and multiple logistic regression analyses. Because of small numbers of rarer cancer types, the cancer type variable was collapsed across low incidence categories to give the following “breast,” “prostate”, and “other” for univariate analysis. Variables of interest included: age category, sex, region of birth, clinically significant anxiety, clinically significant depression, cancer type, and perceived palliative treatment aim. Variables with a \( p \) value of 0.2 or less for univariate analysis were included in a multiple logistic regression model, and the backward stepwise method was used to remove variables with a \( p \) value of 0.1 or greater on the likelihood ratio test. Odds ratios with 95 % confidence intervals were calculated for univariate and multiple regression models and a significance level of 5 % was used. Recruitment site (hospital) was included in the multiple regression analysis to control for between site differences. Analyses were undertaken using STATA version 11.2.

Sample size

This study aimed to recruit a total of 450 patients from four hospital sites, which would allow us to obtain prevalence estimates with 95 % CI’s with ±5 % of the point estimate. This sample size would also allow us to detect differences of 15 % in characteristics between the groups who opt-in and who opt-out of the life expectancy section with a 5 % significance level and 80 % power.

Results

Of the 785 patients screened for eligibility, 126 did not meet the eligibility criteria. Of the 659 patients who were invited to join the study, 570 (86 %) consented to participate in the survey, of whom 82 % (n=469; 71 % of all eligible participants) completed the survey in its entirety. Data was not available for participants who consented but were unable to complete the survey due to time limitations. Participants were 242 males and 227 females, with a mean age of 61.5 years (SD=13.2, median=62.9; Q1, Q3, 52.4, 70.2). At the time of recruitment, respondents were a mean of 85.8 weeks since diagnosis (SD=169.1, median=28.7; Q1, Q3, 16.2, 57.2), and had attended a mean of 11.6 outpatient radiation therapy appointments (SD=10.2, median=9; Q1, Q3, 4, 18). Respondents reported that their most recent primary cancer diagnosis was breast (28 %), prostate (22 %), head and neck (9.6 %), colorectal (bowel; 5.3 %), brain (4.3 %), lung (4.0 %), melanoma (3.4 %), non-Hodgkin’s lymphoma (3.2 %), other cancers (17 %), and 2.1 % did not know. Sixty-nine percent of respondents were Australian born.

Three hundred and twenty-seven (70 %, 95 % CI, 65 %, 74 %) of the 469 participants who completed the survey indicated that they were willing to answer questions about life expectancy. Overall, this meant that 50 % of all eligible participants completed the survey questions about life expectancy. Table 1 outlines the results of the univariate and multiple logistic regression analysis assessing characteristics associated with willingness to complete the life expectancy questions. Following univariate analysis, clinically significant anxiety (\( p=0.3 \)) and perceived palliative treatment aim (\( p=0.5 \)) were excluded from the model (see Table 1). Remaining variables entered into the multiple logistic regression analysis included age group, gender, cancer type, region of birth, and depression. Compared to the youngest age group (18–49 years) those aged 60–69 years and 70 years or more had significantly lower odds of answering the life expectancy questions (see Table 1). Females had significantly lower odds of answering the life expectancy questions than males. Participants born in Asia had lower odds of answering the life expectancy questions than Australian-born participants, and a similar trend was seen for European-born participants (although marginally non-significant). Compared to participants with breast cancer, participants with “other cancers” (i.e., not breast or prostate cancer) had significantly lower odds of completing the life expectancy questions. Having clinically significant depression according to the HADS was not found to be significantly associated with the outcome of interest in the multiple regression model.
In the current study, 70% of participants who completed the survey (and 50% of all eligible patients) were willing to answer a subset of questions about their life expectancy. Previous research into patients’ preferences for life expectancy information has yielded similar consent rates. A large USA-based interview study achieved a consent rate of approximately 70% when assessing the views of 638 advanced cancer patients (recruited from outpatient clinics at seven hospital sites) about whether end of life care discussions had occurred [18]. Australian survey research into cancer patients’ prognostic communication preferences have obtained consent rates of 61% [19]; while interview/focus group studies with palliative care patients have obtained consent rates of up to 83% [20]. However, recruitment for these studies was conducted through oncologists or palliative care services, and poor recruitment for the current study was conducted through eligible patients in outpatient oncology clinics.

### Table 1 Univariate and multiple logistic regression of characteristics of 469 participants completing the patient views survey

<table>
<thead>
<tr>
<th></th>
<th>Willing to complete life expectancy questions</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
<th>Likelihood ratio (\chi^2(\text{df}), p)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>121 (70%)</td>
<td>1</td>
<td>1</td>
<td>4.0 (3), (p=0.2663)</td>
</tr>
<tr>
<td>Site 2</td>
<td>90 (65%)</td>
<td>0.8 (0.4–1.2)</td>
<td>0.8 (0.5–1.3)</td>
<td></td>
</tr>
<tr>
<td>Site 3</td>
<td>51 (68%)</td>
<td>0.9 (0.5–1.6)</td>
<td>1.0 (0.5–1.9)</td>
<td></td>
</tr>
<tr>
<td>Site 4</td>
<td>65 (77%)</td>
<td>1.4 (0.8–2.6)</td>
<td>1.5 (0.8–2.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td>10.7 (3), (p=0.0137)</td>
</tr>
<tr>
<td>18–49</td>
<td>72 (77%)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>73 (72%)</td>
<td>0.7 (0.4–1.4)</td>
<td>0.6 (0.3–1.3)</td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>104 (68%)</td>
<td>0.6 (0.3–1.1)</td>
<td>0.4 (0.2–0.8)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>78 (64%)</td>
<td>0.5 (0.3–1.0)</td>
<td>0.4 (0.2–0.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td>13.9 (1), (p&lt;0.0002)</td>
</tr>
<tr>
<td>Male</td>
<td>179 (74%)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>148 (65%)</td>
<td>0.7 (0.4–1.0)</td>
<td>0.3 (0.2–0.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Region of birth</strong></td>
<td></td>
<td></td>
<td></td>
<td>10.8 (4), (p=0.0291)</td>
</tr>
<tr>
<td>Australia</td>
<td>237 (73%)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>UK and Ireland</td>
<td>26 (67%)</td>
<td>0.7 (0.4–1.5)</td>
<td>0.7 (0.3–1.4)</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>19 (58%)</td>
<td>0.5 (0.2–1.0)</td>
<td>0.4 (0.2–0.8)</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>20 (57%)</td>
<td>0.5 (0.2–1.0)</td>
<td>0.5 (0.2–1.0)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>25 (66%)</td>
<td>0.7 (0.3–1.4)</td>
<td>0.5 (0.2–1.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Palliative treatment aim</strong></td>
<td></td>
<td></td>
<td></td>
<td>13.4 (2), (p=0.0012)</td>
</tr>
<tr>
<td>Yes</td>
<td>43 (73%)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>263 (69%)</td>
<td>1.2 (0.7–2.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>99 (74%)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>79 (75%)</td>
<td>1 (0.6–1.9)</td>
<td>0.5 (0.2–1.1)</td>
<td></td>
</tr>
<tr>
<td>Other*a</td>
<td>149 (65%)</td>
<td>0.6 (0.4–1.0)</td>
<td>0.3 (0.2–0.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Clinically significant anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>44 (58%)</td>
<td>0.8 (0.4–1.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>281 (70%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clinically significant depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15 (65%)</td>
<td>0.6 (0.3–1.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>310 (71%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Observations within each variable may not add to the total due to missing values

*a Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types

*b Assessed using the Hospital Anxiety and Depression Scale

*c Eliminated during backwards stepwise multiple logistic regression analysis

### Discussion

In the current study, 70% of participants who completed the survey (and 50% of all eligible patients) were willing to answer a subset of questions about their life expectancy. Previous research into patients’ preferences for life expectancy information has yielded similar consent rates. A large USA-based interview study achieved a consent rate of approximately 70% when assessing the views of 638 advanced cancer patients (recruited from outpatient clinics at seven hospital sites) about whether end of life care discussions had occurred [18]. Australian survey research into cancer patients’ prognostic communication preferences have obtained consent rates of 61% [19]; while interview/focus group studies with palliative care patients have obtained consent rates of up to 83% [20]. However, recruitment for these studies was conducted through oncologists or palliative care services, and poor recruitment for the current study was conducted through eligible patients in outpatient oncology clinics.
consent rates among oncologists or community nurses may have introduced response bias [19].

Our findings indicating that older participants had lower odds than younger participants of answering questions about life expectancy appear to be consistent with past research. Kaplowitz and colleagues [11] found that older people were significantly less likely to request and to be given prognosis information. Similarly, a review by Fujimori and colleagues reported that younger patients were more likely to express a desire for more prognosis information than older patients [5]. Younger patients may be more likely to have dependent children and be willing to discuss life expectancy information for planning purposes [21]. This may also reflect changes in patient attitudes, preferences, and expectations over time towards increased involvement in cancer treatment decision making [22].

The increased willingness to answer questions on life expectancy among males was contrary to our expectations. It has been reported that women diagnosed with cancer are more likely to want more detailed general information about cancer than men [10]. A study of response rates to an epidemiological survey involving 25,000 participants found that consent to review medical records higher in males older than 50 than females over 50 [23]. Other research has found that men were significantly more likely to be given a quantitative life expectancy estimate than women [11]. Taken together, these findings may suggest that males are more likely to be willing to be involved in research about personal or potentially sensitive issues than females.

Our findings showed that Australian-born participants had higher odds of completing life expectancy questions than respondents born in the Asian region, and marginally non-significantly higher odds than those born in Europe. Previous reports have indicated that culture may influence patients’ preferences for information about life expectancy prognosis discussions [5]. A recent review of patients’ preferences for life expectancy communication reported that studies conducted in Asian countries have reported that fewer than 30 % of patients wish to know about life expectancy, while approximately 60 % of Westerners do [4, 5]. Regional variations in physician views and practices surrounding disclosure of palliative illness status in Europe, Latin America, and Canada have also been reported [24]. These differences may be related to beliefs about the potential impact that awareness of a poor life expectancy estimate may have on patient hope, and consequentially on outcomes. Therefore, the present findings may be reflective of cultural attitudes towards discussion of life expectancy. However, a recent qualitative study looking at communication preferences in migrants to Australia with Greek-, Arabic-, and Chinese-speaking backgrounds, suggests that these migrant groups are possibly more likely than Anglo Australian patients to prefer to have access to prognostic information [25]. It may be that a willingness to answer questions about life expectancy is not comparable to a patient preference to have access to prognostic information. It is also possible that responses regarding willingness to answer life expectancy questions in the current study may have been influenced by family members who may have been accompanying them in the waiting room during survey completion. Further exploration of discordance between patient and family preferences may be warranted in Australian and international settings. However, it does seem likely that some level of cultural variation in patient preferences for answering life expectancy questions exists and further exploration of how this relates to patients preferences for life expectancy disclosure may be warranted. This is particularly pertinent given that individuals without adequate English language to complete the survey were excluded from this study. Future studies should extend these findings to culturally and linguistically diverse communities [25].

Prior research has indicated that patients who identified themselves as having a shorter survival time may be less likely to want, request, and receive life expectancy information compared to those perceiving longer survival time [11]. It has also been suggested that an increased physical burden of cancer may be associated with a preference to have less involvement in cancer care decision making [10]. The current study found no association between patients’ perceived treatment aim and willingness to answer the life expectancy questions. However, individuals in the present study diagnosed with cancers with high 5-year survival rates (i.e., breast or prostate) [1] were more willing than those with other cancers to complete life expectancy questions. It is possible that the greater willingness among breast and prostate cancer patients was linked to perceived length of life. This would appear consistent with the findings of Kaplowitz and colleagues [11]. For instance, increased rates of distress in some poorer prognosis cancer types such as of the lung and brain have been suggested to be associated with feelings of “doom” [26]. This finding warrants further exploration, as the preferences of patients with less common cancers tend to be under reported in current consensus guidelines.

Limitations

This research compared the characteristics of survey participants who were and were not willing to answer a subset of questions about their life expectancy. However, as part of the consent process potential participants were made aware of the optional section about life expectancy, and potential respondents (for whom demographic information is not available) may have opted out at this point. Additionally, although the current study achieved high consent rates to the initial survey (87 %), only 70 % of all eligible patients completed the entire survey in the time available. Once again, demographic information is not available for participants with incomplete surveys, meaning...
comparisons between survey completers and non-completers are not possible. Given that 70% of eligible participants completed the survey in its entirety and 70% of these respondents were willing to answer questions about their life expectancy, overall, 50% of all eligible participants completed the life expectancy questions. Although this overall consent rate is comparable to other research [27], it may limit the external validity of the study results.

All patient demographic and disease data was collected via patient self-report, meaning accuracy for some items is questionable [28]. Accuracy of self-reported cancer history validated against medical records and cancer registry data has been found to be high [29], with high sensitivity in cancer outpatient samples [30].

Implications

There remains a need for high-quality research in the area of life expectancy communication. However, this research needs to minimize the risk of psychological distress to patients while also maximizing the representativeness of samples consulted. This approach to empowering patients to decide whether or not to answer research questions of this nature, rather than having access to patients restricted by clinical gatekeepers, requires a balancing of the ethical principles of beneficence and autonomy [31]. The current study found high consent rates to both the initial survey and also to the life expectancy questions embedded within the main survey, which resulted, in an overall acceptable consent rate. This suggests that this patient-centered approach to researching this sensitive topic was both feasible and acceptable, but the degree of acceptability varied across different subgroups. Further research may be needed to identify how to improve acceptability of this research to subgroups including those who are female, aged 60 years or over, diagnosed with less common cancer types, and Australian migrants from Asian regions [5, 22].

Conclusions

Giving cancer patients the opportunity to opt out of questions about a sensitive issue is a feasible and acceptable option for accessing important information about patient preferences. This method also promotes greater autonomy than clinician-determined methods of access to patients for these types of surveys. Further research may be needed to identify approaches to improve acceptability of research on life expectancy discussions with cancer patients who are older, female, diagnosed with less common cancer types, and who are born in Asia.

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Conflict of interest No authors have reported financial relationships with research sponsoring organizations. Ms Lisa Mackenzie, the corresponding author, had and has full control of the primary data. The authors agree to allow Supportive Care in Cancer to review the data, if requested.

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References

Appendix 1.2: Statements of contribution from co-authors

Statement of contribution

I, Laureate Professor Rob Sanson-Fisher, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


14/08/20

Laureate Professor Rob Sanson-Fisher (Co-Author) Date

16/08/2013

Ms Lisa Mackenzie (Candidate) Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

I, Dr Mariko Carey, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


15/8/ 2013

Dr Mariko Carey (Co-Author) Date

16/08/2013

Ms Lisa Mackenzie (Candidate) Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

I, Professor Catherine D’Este, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


5/8/2013

Professor Catherine D’Este (Co-Author) Date

Ms Lisa Mackenzie (Candidate) Date

Professor John Rostas (Assistant Dean Research & Research Training) Date

12/09/2013
Statement of contribution

I, Miss Alix Hall, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


13/08/2013
Miss Alix Hall (Co-Author)  Date

30/08/2013
Ms Lisa Mackenzie (Candidate)  Date

Professor John Rostas (Assistant Dean Research & Research Training)  Date

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Appendix 2: Paper Two

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Appendix 2.1: Published paper
Do we get it right? Radiation oncology outpatients’ perceptions of the patient centredness of life expectancy disclosure

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Abstract

Objective: A patient-centred approach to discussing life expectancy with cancer patients is recommended in Western countries. However, this approach to eliciting and meeting patient preferences can be challenging for clinicians. The aims of this study were the following: (i) to examine cancer patients’ preferences for life expectancy disclosure; and (ii) to explore agreement between cancer patients’ preferences for, and perceived experiences of, life expectancy disclosure.

Methods: Cancer patients undergoing radiotherapy treatment in metropolitan Australia completed a cross-sectional touchscreen computer survey including optional questions about their life expectancy disclosure preferences and experiences.

Results: Of the 208 respondents, 178 (86%) indicated that they would prefer their clinician to ask them before discussing life expectancy, and 30 (14%) indicated that they would prefer others (i.e. clinicians, family) to decide whether they were given life expectancy information. Of the 175 respondents who were classified as having a self-determined or other-determined disclosure experience, 105 (60%) reported an experience of life expectancy disclosure that was in accordance with their preferences. Cohen’s κ was −0.04 (95% CI, −0.17, 0.08), indicating very poor agreement between patients’ preferences for and perceived experiences of life expectancy disclosure (p = 0.74).

Conclusions: In light of patient-centred prognosis disclosure guidelines, our findings of a majority preference for, and experience of, a self-determined approach to life expectancy disclosure amongst radiation oncology patients are encouraging. However, poor agreement between preferences and experiences highlights that additional effort from clinicians is required in order to achieve a truly patient-centred approach to life expectancy disclosure.

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Introduction

What is a patient-centred approach to life expectancy disclosure?

Many cancer patients, particularly those in Western countries, report concerns and unmet needs relating to cancer prognosis information and communication [1–3]. Western consensus guidelines for prognosis disclosure to cancer patients are in keeping with a patient-centred approach to healthcare [4,5], which argues that patients’ needs, values and preferences should be dominant when negotiating prognosis disclosure [6]. A patient-centred approach requires that the patient and clinician have an explicit understanding of the patient’s preferences for disclosure [7]. It is recommended that cancer clinicians commence a prognosis discussion by asking patients “How much do you want to know about your prognosis?” [4,8,9]. This approach also gives patients the ‘right not to know’ about their life expectancy if they prefer [10], as some cancer patients do not want life expectancy information [11]. These guidelines are based on a combination of expert consensus and descriptive research on patient preferences and experiences [4,5,12–14].

How can we assess whether disclosure practices are aligned with patient-centred guidelines and with patient preferences?

There are a variety of useful methods that can be employed to assess patient–clinician communication in cancer care [15], including patient self-report, carer self-report, clinician self-report, audiotaped/recorded observation and medical records [16,17]. The quality of prognosis communication should not be assessed by whether or not information was provided but by whether it was given in a way that patients can understand, recall, and use to make informed decisions about their healthcare [11].
Research into patient preferences for life expectancy communication has focused on heterogeneous samples of early and advanced stage cancer patients [18]. However, research into patients’ perceived experiences of life expectancy disclosure is largely on the basis of samples of advanced or metastatic cancer patients [19], patients diagnosed with breast cancer or melanoma [20,21] and patients diagnosed with life limiting diseases other than cancer [11,22]. Kaplowitz and colleagues examined concordance between patients’ preferences and experiences of prognosis disclosure in the USA; however, limitations of this study included a low response rate and a sample comprised mostly of females with a previous breast cancer diagnosis (but reporting being cancer free at the time of the study) [23]. To explore the degree to which patient-centred life expectancy disclosure is occurring in clinical practice, there remains a need to explore the concordance between preferences for and perceived experiences of the initiation of life expectancy disclosure amongst a heterogeneous sample of both early and advanced stage cancer patients. This will help to clarify whether current guidelines are consistent with patient preferences, as well as assess the degree to which these patients’ preferences are aligned with their experiences of the initiation of life expectancy disclosure.

Consensus guidelines recommend that clinicians should consider raising the topic of prognosis (including life expectancy) in a range of circumstances, including when patients need to make a decision about treatment [5]. It is recommended that over 50% of cancer patients in Western countries should receive radiation therapy [24]. It would be expected that clinicians may have raised the topic of life expectancy in order to obtain patients’ informed consent for radiotherapy treatment. Therefore, this study focuses on cancer patients receiving radiotherapy.

Aims and hypotheses

The aims of this study were the following: (i) to examine cancer patients’ preferences for who determines whether life expectancy information is disclosed and (ii) to explore the level of agreement between cancer patients’ preferences for, and experiences of, the disclosure of life expectancy information. We hypothesised that patients would prefer to make the decision themselves about whether life expectancy information is disclosed to them, and that this preference would align with patient self-reported experiences of clinical practice [4,5,12,14]. We also aimed to assess disease and demographic factors associated with a patient perception that their preferences for life expectancy disclosure had been met. It was expected that perceived patient-centred communication may be influenced by socio-demographic and disease characteristics including sex [25], age, region of birth, living arrangement, cancer type [26–29], experience of a second diagnosis or recurrence, perceived treatment aim [30], anxiety and depression [31]. It was also expected that an increased opportunity to communicate (possibly resulting from continuing care in the same hospital or with the same doctor) may influence patient perceptions. Therefore, we also explored whether the number of doctor appointments attended and years since diagnosis were associated with a perception of patient-centred communication [32].

Materials and methods

Ethics approvals

Appropriate approvals were obtained from the University of Newcastle and the NSW Population & Health Services Research Ethics Committees.

Patients

Eligibility criteria

Patients aged 18 years or older, receiving adjuvant or palliative outpatient radiation therapy treatment for cancer at one of the four radiation therapy departments and with sufficient English to complete the survey.

Exclusion criteria

Patients who were physically or mentally incapable of completing the survey or who were not currently receiving radiotherapy were excluded by clinic staff.

Setting

The study was conducted in four Australian metropolitan public hospital radiation therapy departments between July and December 2010. Recruitment periods were staggered across the sites as follows: Site 1 (August, September); site 2 (July, September, October); site 3 (October; December); and site 4 (December).

Procedure

Patients waiting for radiation therapy treatment were approached by a trained research assistant, who explained the study purpose and then sought informed consent (taken by survey completion) from eligible patients. The research assistant briefly explained the survey navigation process to consenting patients and commenced the survey by entering the patients’ unique identification number. Touchscreen computer data collection strategies in oncology settings have previously been found to be acceptable to cancer patients [33].

Measures

The patient ‘Cancer Care Survey’ was programmed using Digivey survey software (CREOSO Corporation, Phoenix, Arizona, USA) and administered using a
Patient-centred life expectancy disclosure

touchscreen laptop computer. The survey explored patients’ views of the cancer care they had received, including their perceptions of quality of care [34], psychological characteristics and survey acceptability [35]. Participants were asked to indicate whether or not they were willing to complete questions about their life expectancy. Findings related to characteristics of individuals who were willing to answer these questions are reported elsewhere [36]. A subsample of consecutive respondents who indicated that they were willing to answer questions about their life expectancy questions were also asked to complete the following questions:

Preferences for self-determined disclosure of life expectancy information

Participants were asked to indicate their level of agreement with the statement ‘When discussing life expectancy, I would prefer my doctor to ask me if I want to discuss life expectancy’ on a four-point Likert Scale (1 = strongly disagree; 2 = disagree; 3 = agree; 4 = strongly agree). A preference for self-determined disclosure of life expectancy information was indicated by an ‘agree’ or ‘strongly agree’ response to this question.

Experiences of life expectancy discussions

Respondents were asked to indicate (Yes/No) to the lead question ‘Have you discussed your life expectancy with your cancer doctor?’. If the response to the lead question was ‘yes’, respondents were asked ‘How did the discussion begin?’. If the response to the lead question was ‘no’, respondents were asked, ‘Would you like to talk to your cancer doctor about your life expectancy’ and if ‘yes’, ‘Why haven’t you discussed your life expectancy with your cancer doctor’?

Independent variables

Demographic characteristics

In the first section of the survey, respondents were asked to report their sex, date of birth, country of birth, living arrangement (whether they live with their husband/wife/partner; children/step-children; other family; friends; unrelated flatmates/cotenants or alone) and postcode of usual place of residence.

Disease characteristics

Respondents reported their cancer type; month and year of diagnosis; if they had experienced a second cancer diagnosis or a cancer recurrence; and their perceived treatment aim (to cure the cancer; to prevent the cancer coming back; to control symptoms of the cancer [cure is not possible]). They were also asked to indicate the number of radiotherapy appointments and appointments with their cancer doctor that they had attended.

Psychological characteristics

After the life expectancy questions, respondents completed the 14-item patient self-report Hospital Anxiety and Depression Scale (HADS) to assess the level of anxiety and depression experienced by patients in the week preceding survey completion [37]. This scale has been found to be an effective indicator of psychological distress in cancer patients undergoing treatment [38]. Patients meeting or exceeding HADS anxiety and HADS depression subscale scores of 11 are classified with likely anxiety and depression, respectively [39].

Statistical analysis

Patient preferences were coded into a dichotomous variable (patient self-determined disclosure of life expectancy information versus other-determined disclosure of life expectancy information). Patient experience data was similarly coded. The percentage of patients preferring self-determined disclosure of life expectancy information was estimated with 95% confidence interval (CI). Cohen’s $\kappa$ was used to assess whether the agreement between patient’s preferences for, and experiences of, disclosure of life expectancy information was greater than expected by chance. The observed percentage of agreement and Cohen’s $\kappa$ were estimated with 95% CI’s, and extent of agreement between patients’ preferences and experiences was assessed amongst those classified as having a self- or other-determined disclosure experience [40]. Those who were not able to be classified into these categories of disclosure experience were excluded from further analysis. McNemar’s test was used to assess marginal homogeneity. Univariate and multiple logistic regression analyses was used to examine variables expected to be associated with a patient perception that their preferences for life expectancy disclosure had been met: sex [25], age (calculated using date of birth and date of survey completion), region of birth (classified from self-reported country of birth), living with a partner, cancer type [26–29], experience of a second diagnosis or recurrence, perceived palliative treatment aim [30], HADS classified likely anxiety and depression [31], number of doctor appointments and approximate time because diagnosis (number of years calculated from patient self-reported year and month of diagnosis and date of survey completion) [32]. Recruitment site (hospital) was included in the multiple regression analysis, along with variables with a univariate analysis $p$-value of 0.2 or less. The backward stepwise method was then used to remove variables with a $p$-value of 0.1 or greater on the likelihood ratio test. Odds ratios with 95% confidence intervals are reported. Analysis was conducted using STATA Version 11.2 (StataCorp LP, College Station, Texas, USA) and a significance level of 5%.
Sample size

A total of 200 patients completing the life expectancy questions would allow us to obtain prevalence estimates with 95% CI’s within ±7% of the point estimate (assuming approximately 60% of patients will prefer self-determination), and an estimate of kappa with 95% CI’s within ±15% (assuming kappa of 0.5 or more). This sample size would also allow detection of differences in characteristics of 20% for binary explanatory variables and 0.4 standard deviations for continuous explanatory variables (between patients whose perceived life expectancy disclosure experience did and did not meet their preference), with 5% significance level and 80% power.

Results

Response rate

Of the 529 patients screened for eligibility (based on availability of clinic staff, research assistants and touchscreen computers), 98 were recorded as being ineligible. Primary reasons for ineligibility included having inadequate English (n = 45; 8.5%) and not being a current radiotherapy patient (n = 29; 5.5%). Of the 431 eligible patients, 370 (86%) agreed to participate in the survey, and 307 (83%) completed the survey, meaning that overall 71% of eligible patients provided complete data. There were significantly larger proportion of male non-consenters than female non-consenters (p = 0.03). Sixty-eight percent (n = 208) of participants additionally agreed to complete the optional life expectancy survey component. The individuals who completed the life expectancy component will hereafter be referred to as respondents. Respondents were an average age of 61.1 years (SD = 13.4). The most common cancer types were breast (28%), followed by prostate (25%) and head and neck cancer (9.1%). Table 1 shows additional disease and demographic characteristics of the sample.

Preferences for disclosure

Of the respondents, 178 (86%; 95% CI, 80%, 90%) had a preference for self-determined life expectancy disclosure decision making. Demographic characteristics of these 178 respondents are presented in Table 1.

Perceptions of life expectancy disclosure

Figure 1 shows the response pathways leading to classification as a perceived self-determined, other-determined or unclassified disclosure experience, the numbers of respondents following each pathway and disclosure preferences amongst each group. Table 2 shows the proportion of respondents reporting experiences of life expectancy disclosure aligned with their preferences. Of the 175 respondents classified in

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample n (row %)</th>
<th>Preference for self-determined disclosure n (column %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–49</td>
<td>208 (94)</td>
<td>178 (86%)</td>
</tr>
<tr>
<td>50–59</td>
<td>48 (23)</td>
<td>43 (90)</td>
</tr>
<tr>
<td>60–69</td>
<td>65 (31)</td>
<td>59 (91)</td>
</tr>
<tr>
<td>70+</td>
<td>53 (25)</td>
<td>38 (72)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>115 (55)</td>
<td>95 (83)</td>
</tr>
<tr>
<td>Female</td>
<td>93 (45)</td>
<td>83 (89)</td>
</tr>
<tr>
<td>Region of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>148 (71)</td>
<td>125 (84)</td>
</tr>
<tr>
<td>UK and Ireland</td>
<td>19 (9.1)</td>
<td>16 (84)</td>
</tr>
<tr>
<td>Continental Europe</td>
<td>15 (7.2)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>Asia</td>
<td>11 (5.3)</td>
<td>11 (100)</td>
</tr>
<tr>
<td>Other</td>
<td>15 (7.2)</td>
<td>15 (100)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34 (17)</td>
<td>32 (94)</td>
</tr>
<tr>
<td>No</td>
<td>167 (83)</td>
<td>140 (84)</td>
</tr>
<tr>
<td>Second diagnosis or recurrence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>63 (32)</td>
<td>53 (84)</td>
</tr>
<tr>
<td>No</td>
<td>136 (68)</td>
<td>117 (86)</td>
</tr>
<tr>
<td>Cancer type</td>
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<td></td>
</tr>
<tr>
<td>Breast</td>
<td>59 (28)</td>
<td>48 (81)</td>
</tr>
<tr>
<td>Prostate</td>
<td>53 (25)</td>
<td>43 (81)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>19 (9.1)</td>
<td>18 (95)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>12 (5.8)</td>
<td>10 (83)</td>
</tr>
<tr>
<td>Lung</td>
<td>10 (4.8)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Brain</td>
<td>7 (3.4)</td>
<td>6 (86)</td>
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<tr>
<td>Non-Hodgkin’s Lymphoma</td>
<td>6 (2.9)</td>
<td>6 (100)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>6 (2.9)</td>
<td>6 (100)</td>
</tr>
<tr>
<td>Other</td>
<td>32 (15.4)</td>
<td>30 (94)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4 (1.9)</td>
<td>3 (75)</td>
</tr>
<tr>
<td>Likely anxietya</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27 (13)</td>
<td>26 (96)</td>
</tr>
<tr>
<td>No</td>
<td>179 (89)</td>
<td>150 (84)</td>
</tr>
<tr>
<td>Likely depressiona</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (4.4)</td>
<td>9 (100)</td>
</tr>
<tr>
<td>No</td>
<td>197 (96)</td>
<td>167 (85)</td>
</tr>
<tr>
<td>Living withb</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband/wife/partner</td>
<td>141 (68)</td>
<td>120 (85)</td>
</tr>
<tr>
<td>Children/stepchildren</td>
<td>38 (18)</td>
<td>32 (84)</td>
</tr>
<tr>
<td>Other family</td>
<td>14 (67)</td>
<td>13 (93)</td>
</tr>
<tr>
<td>Friends</td>
<td>5 (2.4)</td>
<td>4 (80)</td>
</tr>
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<td>Unrelated flatmate/co-tenant</td>
<td>2 (1.0)</td>
<td>2 (100)</td>
</tr>
<tr>
<td>Alone</td>
<td>39 (19)</td>
<td>33 (85)</td>
</tr>
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</table>

 Median (Q1, Q3) Median (Q1, Q3)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of radiation treatments</th>
<th>Number of appointments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8.5 (4, 15)</td>
<td>3.4 (2, 4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>with cancer doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Years since diagnosis</td>
</tr>
<tr>
<td></td>
<td>0.6 (0.3, 1.4)</td>
<td>0.6 (0.3, 1.5)</td>
</tr>
</tbody>
</table>

Numbers may not add up to total due to missing data. Due to rounding, percentages may not add up to total.

*a* Determined as meeting or exceeding a HADS subscale threshold score of 11.

*b* The first five categories were not mutually exclusive, so percentage exceeds 100%.

Figure 1 as having a patient-determined or other-determined life expectancy disclosure experience, 105 (60%; 95% CI, 52%, 67%) experienced life expectancy...
disclosure practices aligned with their preferences. Cohen’s $\kappa$ was $-0.04$ (95% CI, $-0.17$, 0.08). This indicated poor agreement between respondents’ preferences for and experiences of life expectancy disclosure, which was not significantly greater than expected by chance ($Z = -0.65$, $p = 0.74$). For this population, there was a difference between the experiences of individuals who preferred other-determined and those who preferred self-determined disclosure of life expectancy information. Those with a preference for other-determined life expectancy disclosure were less likely to experience disclosure in line with their preferences than those with a preference for self-determined disclosure decision making ($\chi^2 (1) = 16.5, p < 0.0001$).

Of the 150 respondents who indicated a preference for self-determined life expectancy disclosure decision making, 98 (65%, 95% CI, 57%, 73%) perceived that their experiences of life expectancy disclosure were aligned with their preferences. Of the 25 respondents indicating a preference for other-determined life-expectancy disclosure decision making, seven (28%, 95% CI, 12%, 49%) reported that their experiences aligned with their preferences.

**Variables associated with a perception that disclosure preferences were met**

Females had 3.0 times the odds of males of having a perception that their preferences for life expectancy disclosure were met (95% CI, 1.6, 5.9), $\chi^2 (1) = 11.4$, $p = 0.0007$). The odds of perceiving that disclosure preference had been met was found to increase by 20% per additional year since diagnosis (95% CI, 1.0, 1.4), $\chi^2 (1) = 6.3$, $p = 0.0119$.

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**Table 2. Proportion of patients reporting experiences of life expectancy disclosure in alignment with preferences (n = 175)**

<table>
<thead>
<tr>
<th>Patient preference</th>
<th>Self-determined disclosure</th>
<th>Other-determined disclosure</th>
<th>Total</th>
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</thead>
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<tr>
<td>Self-determined disclosure</td>
<td>98 (65%)</td>
<td>52 (35%)</td>
<td>150</td>
</tr>
<tr>
<td>Other-determined disclosure</td>
<td>18 (72%)</td>
<td>7 (28%)</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>59</td>
<td>175</td>
</tr>
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*aRow percentages.*
Discussion

Preferences for life expectancy disclosure

The majority of respondents (86%) preferred that their cancer doctor ask them before discussing the impact that cancer might have on their life expectancy. Respondent preferences are closely aligned with consensus guidelines for a patient-centred approach to disclosure. It should be noted that within the bounds of previous findings (2–38%) [41,42], a minority of respondents (14%) preferred life expectancy disclosure decisions to be made by others (e.g. clinicians, partners, family members). Characteristics of the sample with a preference for self-determined disclosure were presented but not formally tested because of the small proportion of patients with a preference for other-determined disclosure. It has been suggested that this preference for other-determined disclosure may vary due to cultural factors [43] and variations in individual coping style or adjustment [44]. A preference for other-determined disclosure of life expectancy information does not appear to be compatible with the recommended patient-centred approach, making it difficult for clinicians to navigate an appropriate approach to disclosure for these individuals [7] within the context of shared decision making, patient confidentiality and autonomy [45,46]. Guidelines currently acknowledge this dilemma [5,18].

Although the aforementioned minority preference for other-determined initiation of life expectancy disclosure poses a dilemma for clinicians [41,42,47], improving clinician adherence to the recommended patient-centred prognosis disclosure practice would increase responsiveness to the majority preference for self-determined disclosure. Recent reviews have identified some factors that may be associated with a preference for other-determined disclosure (i.e. older age; male sex; low levels of distress and anxiety; and a family-centred cultural background) [43]. However, assessment of patient preferences at the level of the individual is still crucial [5,48]. A potential way forward for clinicians may be to explore early on whether patients would prefer (i) their clinician to take responsibility for initiating a life expectancy discussion when they view it as important; or (ii) to take responsibility themselves for as initiating a life expectancy discussion if and when they want this information [49].

Agreement between respondents’ preferences and experiences

In the present study, only 60% of the respondents reported experiences of life expectancy disclosure aligned with their preferences. Kaplowitz and colleagues reported that 73% of their sample had received quantitative life expectancy estimates in accordance with their preferences [23]. It should be noted that the Kaplowitz study assessed whether patients wanted information about how long they might live [23], whereas the present study more specifically assessed patients’ preferences for initiation of life expectancy discussions. In addition, the present study was more representative of gender and patients undergoing treatment close to time of diagnosis than the Kaplowitz study [23]. Our findings also suggest that respondents who express a preference for other-determined disclosure are more likely to report that they miss out on receiving their preferred disclosure approach in clinical practice. This suggests that although there has been a shift towards guideline recommended patient self-determined prognosis disclosure practices, there is still room for improvement to achieve truly patient-centred care.

Factors associated with a perception that preferences for disclosure were met

Despite having a smaller sample size than planned available for analysis, the current study identified higher odds of a respondent perception that their preferences for life expectancy disclosure had been met (i.e. that life expectancy disclosure was patient-centred) for females compared with males and for individuals with a longer versus shorter time since diagnosis. It has previously been reported that compared with males, females are more likely to want, and ask for, information about prognosis [25,50]. Males were more likely to be given a quantitative life expectancy estimate than females, whether or not they asked for it [23]. These factors may have contributed to the discrepancies in perceived patient-centred care between males and females in the present study. As a longer time since diagnosis is likely to be associated with increased opportunities for a strengthened patient–clinician relationship, communication is likely to become more patient-centred further from the time of diagnosis [32]. However, it should be noted that clinicians are also more likely to overestimate survival in longer-term patient-clinician relationships [51]. As previous research investigating experiences of prognosis disclosure has largely focused on patients with advanced and metastatic cancer [19–21], this finding emphasises the need for improvements in patient-centred prognosis disclosure to patients making treatment decisions close to the time of diagnosis.

Given the mismatch identified between respondents’ preferences and experiences for life expectancy disclosure for specific patient groups, there is a need to consider potential methods for shifting current practices towards a more patient-centred approach. Targeted communication, shared decision making and bioethics education interventions that focus on clinical interactions with male patients and cancer patients’ making treatment decisions close to the time of diagnosis may be the most appropriate next steps for changing practice in this area [18,52–54].
Limitations

The degree to which we can generalise from these findings may be limited by the lower completion rate of the life expectancy section compared with completion rates for the main survey [36]. Overall, only 48% of those eligible to participate completed the survey and the optional section on life expectancy. In our previous assessment of factors associated with opting out of these life expectancy questions, patients who were female, older and diagnosed with cancer types other than breast and prostate had lower odds of answering the life expectancy questions [36]. There was also an association between lower odds of answering the life expectancy questions and being in Asia [36]. It is also noteworthy that only 16% of the sample perceived that their treatment aim was palliative, whereas it has been suggested that approximately 40% of radiation therapy courses are delivered with palliative intent [55]. This may reflect that some patients are not aware of the aim of their treatment, or alternatively, that patients with poorer prognosis cancer types may be less likely to answer questions about life expectancy [36] or to be considered eligible for and consent to survey research in this setting. Taken together, these characteristics suggest that the study sample may have been skewed towards younger, Australian-born patients being treated with curative intent, possibly limiting generalisability of the findings. Despite these limitations, the life expectancy question completion rate of 48% reported in this study is only slightly lower than consent rates of 58% obtained in a similar Australian study [56]. The present study extends on this past research by providing valuable information about the concordance between patients’ preferences and experiences of life expectancy discussions outside advanced or metastatic melanoma or breast cancer patient populations [19–21].

Some limitations of patient self-report should also be noted. Although respondents were asked a generic question about whether they had discussed life expectancy with their ‘cancer doctor’, conducting the survey in a radiotherapy setting may have influenced patients to only consider communications with their radiation oncologist. Secondly, it is difficult for patients to determine whether their doctor has fully or partially disclosed information about their life expectancy following patient self-determined life expectancy discussion initiation. This may suggest that alignment of life expectancy disclosure with the preference held by the majority of respondents (self-determined disclosure) is lower than the 65% reported here. However, given that the survey respondents who opted out of the life expectancy section were probably more likely to have had a preference for other-determined disclosure; the true proportion of patients preferring self-determined disclosure may be smaller than identified in this study. This emphasises the need to broaden our understanding of what predicts patients’ preferences for life expectancy disclosure in order to support clinical decision making in this area.

We intentionally focused on patients’ perceptions of life expectancy discussions for the purposes of this study. However, future research could combine this method with more objective observational methods to assess life expectancy disclosure practices [46,57,58]. This could provide insight into possible reasons for non-concordance between doctors and patients regarding life expectancy communication.

Conclusions

Although preferences for a self-determined approach to life expectancy disclosure are consistent with clinical practice guidelines, our findings suggest that patient reported experiences in clinical practice are not always aligned with this preference. We found that males and patients with less time since their cancer diagnosis had lower odds of perceiving patient-centred life expectancy disclosure. This suggests a need for targeted interventions to assist both patients and clinicians with communication skills for bringing prognosis disclosure into alignment with the recommended patient-centred approach for these patient groups.

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References


1. Epstein DE. The
Patient-centred life expectancy disclosure


Appendix 2.2: Statements of contribution from co-authors

Statement of contribution

I, Laureate Professor Rob Sanson-Fisher, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


14/08/2013

Laureate Professor Rob Sanson-Fisher (Co-Author) Date

16/08/2013

Ms Lisa Mackenzie (Candidate) Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

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Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training)

Date
Statement of contribution

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Professor John Rostas (Assistant Dean Research & Research Training) Date

12/09/2013
Statement of contribution

I, Associate Professor Christine Paul, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


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Ms Lisa Mackenzie (Candidate)  Date

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Appendix 3: Paper Three

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Appendix 3.1: Published paper
Abstract

Purpose The objective of this study was to examine the likely presence of, and factors associated with, anxiety, depression and overall psychological distress in cancer outpatients undergoing radiation therapy treatment in Sydney, Australia.

Methods A touchscreen computer survey was conducted in four radiation therapy treatment centre waiting rooms. Patients waiting to receive treatment completed the survey which included questions about demographic and disease characteristics, survey acceptability and the Hospital Anxiety and Depression Scale (HADS).

Results A total of 454 patients (70 %) completed the touchscreen computer survey. The likely presence of anxiety (HADS-A ≥11), depression (HADS-D ≥11) and overall psychological distress (HADS-T ≥15) was 15, 5.7 and 22 %, respectively. Cancer type was found to be associated with each HADS screening category. The majority of patients reported high survey acceptability and willingness to complete similar touchscreen computer surveys in the treatment centre waiting room on additional occasions.

Conclusions As radiotherapy patients frequently attend the radiation oncology department, routine screening and intervention for elevated levels of psychological distress in this setting appears to be feasible. High survey completion rates and high patient-rated acceptability support this approach to screening. The likely presence of psychological distress is reported for this sample; however, the selection of HADS threshold scores is likely to have influenced the reported rates. Further research is needed to identify how cancer type impacts on likely caseness across the different HADS classifications examined.

Keywords Anxiety · Depression · Cancer · Radiotherapy · Touchscreen computers · HADS

Introduction

Cancer and assessment of psychological distress

Cancer is a leading cause of morbidity and mortality, with an estimated 12.7 million new cancer cases and 7.6 million cancer deaths worldwide in 2008 [1]. Cancer has also been associated with elevated levels of psychological distress [2–4]. Undetected and untreated psychological distress may have implications for important patient outcomes, including treatment adherence, level of self-care, length of hospital stays and service use [3, 5]. Routine screening for psychological distress in oncology settings has been recommended; however, it has not been widely adopted [6]. Further exploration of the acceptability of distress screening in clinical settings is warranted.

Why focus on radiation therapy patients?

It is recommended that approximately half of all new cancer patients should receive radiation therapy (RT) [7]. RT is usually delivered on an outpatient basis through cancer
treatment centres on a Monday–Friday schedule over 2–8 weeks [8, 9]. It has been suggested that this intensive treatment period may provide a valuable opportunity for screening and intervening for psychological distress [10, 11]. Despite the large body of research on prevalence and factors associated with psychological distress in cancer patients [3, 12–14], only a small number of studies have focused on RT patients during treatment [9]. Amongst existing studies, the use of relatively small sample sizes [15, 16] and a focus on a limited range of cancer types [17] has limited the degree to which these findings can be generalised to all cancer patients undergoing RT treatment.

Why examine factors associated with poorer psychosocial outcomes in radiation oncology patients?

Identification of factors associated with poorer psychosocial outcomes in RT patients may aid the radiation oncology health care team in identifying patients who may be in need of additional psychosocial support. For instance, studies in oncology patients have suggested that cancer patients who are younger [12, 15, 18], female [12, 18, 19] and perceive that their treatment aim is palliative [20] may be more likely to suffer from elevated levels of psychological distress. It has also been suggested that other demographic factors such as ethnicity [12, 21] and cancer type [13] may influence rates of distress. To the best of our knowledge, this is the first Australian study of psychological distress in a large, heterogeneous sample of radiation oncology outpatients who are currently undergoing treatment [9]. This study aimed to establish in a radiation oncology patient population: (1) the likely presence of (a) anxiety, (b) depression and (c) overall distress using the HADS and (2) factors associated with a likely presence of (a) anxiety, (b) depression and (c) overall distress. We also assessed the acceptability of a touchscreen computer survey conducted in RT treatment waiting rooms to investigate the likely presence of psychological distress.

Patients and methods

Design

This was a cross-sectional patient survey.

Participants

Cancer outpatients were recruited from four metropolitan RT treatment centres attached to large public hospitals in Australia between February and December 2010. Eligibility criteria included being aged 18 years or older; having a cancer diagnosis; receiving RT treatment; and understanding sufficient English to complete the patient survey.

Ethical standards

Human research ethics approvals were obtained from The University of Newcastle and the New South Wales Population and Health Services Research Ethics Committee. Research governance authorisations were also obtained from participating hospitals.

Procedure

A research assistant (RA) attended the radiation oncology departments. Patients waiting for their RT treatment were invited to participate based on the availability of the RA and touchscreen computers. Informed consent was sought from eligible patients. Consenting patients were allocated a unique identification code to login to the touchscreen computer survey, which they completed whilst waiting for their RT treatment.

The survey was programmed into a Dell Latitude XT2 touchscreen computer using Digivey survey software (CREOSO Corporation, Arizona). Touchscreen computer surveys assessing psychological distress and completed in an oncology waiting room have been previously found to be acceptable to cancer patients [22]. The following modules were embedded within a larger survey:

The Hospital Anxiety and Depression Scale The Hospital Anxiety and Depression Scale (HADS) is a brief (14-item) patient self-report measure of anxiety and depression requiring respondents to report their symptoms during the previous week [23]. The HADS has demonstrated reliability and validity in cancer patient populations [24] and has been found to be an effective screening tool for cancer patients currently undergoing treatment [25]. Additionally, HADS scores have been found to be comparable when administered by touchscreen computer and pen-and-paper modes [26].

The sensitivity and specificity of the HADS are influenced by the threshold scores used to identify a likely presence of anxiety and depression [27, 28]. The HADS is divided into anxiety (HADS-A) and depression (HADS-D) subscales. Subscale scores of 0–7 are classified as normal; 8–10 as mild; 11–14 as moderate; and 15–21 as severe [29]. Subscale scores ranging from 8 [24, 30] to 11 [31] are typically used for identifying the possible presence of anxiety and depression. Cancer research has extensively applied...
subscales of 11 to indicate the likely presence of anxiety and/or depression, reported as achieving 70–95 % sensitivity and 83 % specificity [32]. Although the use of the HADS total score (HADS-T) was not recommended by the scale developers [23], recently, HADS-T scores of 10–15 have been used to indicate the likely presence of overall psychological distress. Ibbotson et al. [25] found that a HADS-T threshold score of ≥15 resulted in 80 % sensitivity, 76 % specificity and a positive predictive value of 41 % for detecting generalised anxiety disorder or major depressive illness as assessed by the Psychiatric Assessment Schedule. This HADS-T threshold has also been applied in similar studies examining cancer patients' psychological distress.

Demographic and disease explanatory variables Participant age; sex; cancer diagnosis; time since diagnosis; country of birth; and treatment aim were collected via patient self-report. Self-reported clinical information, including reporting of cancer site and time since diagnosis, in this population has been found to provide reliable when compared to cancer registry records [33].

Acceptability of touchscreen computer survey A subsample of consecutive patients completed investigator-derived items assessing the acceptability of the touchscreen computer survey. Respondents were asked how much they agreed with a series of statements on a four-point Likert scale (strongly disagree, disagree, agree and strongly agree). Statements included “The instructions were easy to follow”; “The questions were easy to understand”; “The touchscreen was easy to use”; “I had enough time to answer all the questions”; “I felt comfortable answering the questions”; and “The touchscreen allowed enough privacy”. Respondents were also asked to indicate on how many visits to the treatment centre they would be prepared to complete a similar touchscreen computer survey. Response options were: “only once (just this survey)”; “less than half the visits”; “half of the visits”; “most visits”; or “every visit”.

Statistical analysis

HADS-A and HADS-D subscale scores were calculated for each participant. The proportion with scores meeting or exceeding threshold scores for moderate–severe levels (≥11) on each subscale was calculated with 95 % confidence interval (CI). The proportion of participants with a likely presence of psychological distress defined as total HADS threshold score of ≥15 was also reported with 95 % CIs. Univariate logistic regression analyses were then used to identify factors associated with a likely presence of anxiety, depression and overall distress. Variables with a p value of 0.2 or less were included in the multiple logistic regression models. Variables examined at univariate level included: age (18–49 years; 50–59 years; 60–69 years; and 70 years or more), sex, country of birth (Australian born and not Australian born), cancer type (breast, prostate, other common cancer and other cancer) and perceived treatment aim (palliative and not palliative). The backward stepwise method was used to remove variables with a p value of 0.1 or greater on the likelihood ratio test [34]. Recruitment site (hospital) was included in the multiple regression analysis to account for the sampling strategy. Odds ratios with 95 % confidence intervals are reported for univariate and multiple regression models, and a significance level of 5 % used. The proportion of patients reporting that they agreed or strongly agreed with each of the acceptability items are also reported with 95 % CIs. Analyses were undertaken using Stata version 11.2.

Sample size

This study aimed to invite 600 eligible patients from the four hospital sites to participate. Assuming a survey consent and completion rate of 75 %, this would provide 450 respondents. Based on prevalence rates previously found in oncology settings, this would allow us to obtain prevalence estimates with 95 % CIs within ±3 % of the point estimate for likely anxiety and depression and ±4 % of the point estimate for likely psychological distress. This sample size would also be sufficient to detect differences in characteristics between those with and without the outcome of interest of 20 % for anxiety and psychological distress and 25 % for depression. Assuming 90 % acceptability, a subsample of 160 patients would also allow us to obtain prevalence estimates with 95 % CIs within ±5 % of the point estimate for the acceptability items.

Results

Patient characteristics

Of the 785 patients screened for eligibility, 659 were considered eligible to participate and were invited to join the study. Reasons for ineligibility included inadequate English (n=60); not currently receiving RT (n=21); clinic staff noted ineligibility regarding inpatient status and/or in ability to give informed consent (n=13); and if the patient had already been approached about the survey (n=6), was not diagnosed with cancer (n=4) or was under the age of 18 (n=2). For 13 patients, the specific reason for ineligibility was not recorded. Of the eligible patients, 570 (86 %) agreed to participate. Surveys with completed HADS were obtained from 454 (70 % of eligible patients) who are classified as respondents for the purposes of this study. Incomplete data generally resulted from respondents
being called into their appointment before survey completion. Twelve completed surveys with responses indicating that the respondent was attending an outpatient appointment other than treatment were excluded from further analysis to fit with eligibility criteria for this study. The first 159 consecutive respondents answered the survey acceptability items.

Of the respondents, 233 (51 %) were male, 221 (49 %) were living with a husband, wife or partner, 98 (22 %) were living with children/stepchildren, 30 (6.6 %) with other family, 9 (2.0 %) with friends, 6 (1.3 %) with an unrelated flatmate or covenant, 90 (20 %) were living alone and 315 (69 %) were born in Australia. The mean age was 61.2 years (SD=13.1), ranging from 18.9 to 91.4 years. Fifty-nine participants (13 %) perceived that their treatment aim was palliative. One hundred and thirty-one participants (29 %) were diagnosed with breast cancer, 100 (22 %) with prostate cancer, 44 (9.8 %) with head and neck cancer, 23 (5.1 %) with colorectal (bowel) cancer, 20 (4.4 %) with brain cancer, 19 (4.2 %) with lung cancer, 16 (3.6 %) with melanoma, 15 (3.3 %) with non-Hodgkin’s lymphoma, 9 (2 %) did not know and 73 (16 %) had other cancer types. Respondents were a median of 28.4 weeks since diagnosis (Q1, Q3; 16.1, 55.6).

Participants identified as likely cases on the HADS-A, HADS-D and HADS-T

Sixty-eight respondents (15 %; 95 % CI 11–18 %) met or exceeded threshold scores for the likely presence of moderate–severe anxiety and 26 (5.7 %; 95 % CI 3.6–7.9 %) for the likely presence of moderate–severe depression. The HADS threshold score of 15 was met or exceeded in 102 participants (22 %; 95 % CI 19–27 %), indicating the likely presence of psychological distress.

Factors associated with a likely presence of anxiety, depression and distress

Tables 1, 2 and 3 show the initial and final multiple logistic regression models for respondents with and without a likely presence of anxiety, depression and psychological distress, respectively. As seen in Table 1, for HADS categorised moderate–severe anxiety, the variables age, sex and cancer type were included in the multiple logistic regression analysis. A diagnosis of prostate cancer was also associated with lower odds (0.2) of a likely presence of anxiety compared to the breast cancer reference group. Additionally, respondents in the older age category (aged 70 or above) had marginally significantly lower odds of a likely presence of anxiety compared to the youngest age group (18–49 years old).

Table 2 shows that for a HADS categorised likely presence of depression, age, cancer type and palliative treatment aim were included in the initial model for multiple regression analysis. Respondents diagnosed with other common cancers (including brain, colorectal, head and neck, lung, melanoma and non-Hodgkin’s lymphoma) had 3.4 times the odds of having a likely presence of depression compared with the breast cancer reference category.

The variables age, sex and cancer type were included in the initial model for multiple regression analysis of the likely presence of psychological distress outcome (see Table 3). Compared with the breast cancer reference group, respondents with a diagnosis of prostate cancer had lower odds (0.2) of having a likely presence of psychological distress.

Survey acceptability

Of the 159 respondents, the majority agreed that the touchscreen computer survey that they had just completed was easy to use (99 %; 95 % CI 96–100 %), allowed enough privacy (99 %; 95 % CI 97–100 %), had questions that were easy to understand (96 %; 95 % CI 92–99 %), instructions that were easy to follow (99 %; 95 % CI 96–100 %) and that they felt comfortable answering the questions (99 %; 95 % CI 97–100 %). Overall, 111 participants (70 %; 95 % CI 62–77 %) indicated that they would be willing to complete a touchscreen computer survey while waiting for the RT appointment on more than one visit to the radiotherapy treatment centre. Thirteen percent (95 % CI 7.9–19 %) said they would be willing to do this on less than half the visits, 15 % (95 % CI 9.9–22 %) on half of the visits, 28 % (95 % CI 21–36 %) on most of the visits and 14 % (95 % CI 8.9–20 %) on every visit.

Discussion

Proportion of outpatients with a likely presence of anxiety, depression and distress

Using HADS subscale threshold score of 11, a likely presence of anxiety was observed in 15 % of participants and depression in 5.6 %. Previous studies conducted in the UK using the HADS have reported anxiety between 9 and 19 % and depression in between 5 and 9 % of radiotherapy patients [15, 35]. Similarly, Pascoe et al. [12] found that in a sample of 504 Australian oncology outpatients (of whom 41 % were receiving radiotherapy), approximately 12 % were likely cases of anxiety and 7 % were likely cases of depression.

Debate remains about whether it is most appropriate to use the HADS total score or the subscale scores, which allow bi-dimensional assessment of anxiety and depression [36, 37]. In the present study, using a HADS-T threshold of ≥15, close to one quarter of respondents were identified with a likely presence of psychological distress. This is consistent with research applying the same total threshold score recommended by Ibbotson et al. [25]. Strong et al. [14] and Sharpe et
Table 1  Multiple logistic regression analysis of demographic and disease characteristics of those with a HADS classified likely presence of anxiety

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Likely presence of anxiety&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Unadjusted OR (95 % CI)</th>
<th>Likelihood ratio chi&lt;sup&gt;2&lt;/sup&gt; (df), p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>26 (16 %)</td>
<td>1</td>
<td>0.7 (3), p=0.9</td>
</tr>
<tr>
<td>Site 2</td>
<td>19 (15 %)</td>
<td>0.9 (0.5–1.8)</td>
<td>1.1 (0.6–2.3)</td>
</tr>
<tr>
<td>Site 3</td>
<td>12 (16 %)</td>
<td>1.0 (0.5–2.2)</td>
<td>1.1 (0.5–2.3)</td>
</tr>
<tr>
<td>Site 4</td>
<td>9 (11 %)</td>
<td>0.6 (0.3–1.4)</td>
<td>0.8 (0.3–1.9)</td>
</tr>
</tbody>
</table>

Observations within each variable may not add to the total due to missing values

<sup>a</sup>Includes brain cancer, colorectal cancer, head and neck cancer, lung cancer, and non-Hodgkin’s lymphoma

<sup>b</sup>Assessed using the Hospital Anxiety and Depression Scale (HADS) anxiety subscale threshold score of ≥11

Table 2  Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of depression

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Likely presence of depression&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Unadjusted OR (95 % CI)</th>
<th>Likelihood ratio chi&lt;sup&gt;2&lt;/sup&gt; (df), p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>12 (7.2 %)</td>
<td>1</td>
<td>5.2 (3), p=0.2</td>
</tr>
<tr>
<td>Site 2</td>
<td>6 (4.6 %)</td>
<td>0.6 (0.2–1.7)</td>
<td>0.8 (0.3–2.2)</td>
</tr>
<tr>
<td>Site 3</td>
<td>7 (9.5 %)</td>
<td>1.3 (0.5–3.6)</td>
<td>1.3 (0.5–3.5)</td>
</tr>
<tr>
<td>Site 4</td>
<td>1 (1.2 %)</td>
<td>0.2 (0.02–1.2)</td>
<td>0.2 (0.02–1.5)</td>
</tr>
</tbody>
</table>

Observations within each variable may not add to the total due to missing values

<sup>a</sup>Includes brain cancer, colorectal cancer, head and neck cancer, lung cancer, and non-Hodgkin’s lymphoma

<sup>b</sup>Assessed using the Hospital Anxiety and Depression Scale (HADS) depression subscale threshold score of ≥11
al. [38] conducted studies in cancer patient populations in the UK and identified a likely presence of distress using the HADS total score in 22 and 23 % of patients, respectively.

Factors associated with a likely presence of anxiety, depression and distress

Respondents aged 70 or more had marginally significantly lower odds of experiencing a likely presence of anxiety according to the HADS than the younger respondent group aged 18–49 years. It has been previously reported that younger cancer patients are likely to experience more severe distress [39]. However, Aass et al. [18] identified lower levels of anxiety in Norwegian cancer patients under 30 and over 70, suggesting anxiety was greater in middle-aged cancer patients. Pascoe et al. [12] did not find any association between age group and anxiety or depression using a binary categorisation of age group (<65 and ≥65). It seems likely that the categorical groupings of age across these studies may relate to the discrepancies between these findings. In the current study, the youngest age group (and reference category) was from 18 to 49 years. It is possible that lower anxiety in respondents aged less than 30 was not detected because of this categorisation; however, due to the low numbers of respondents aged less than 30 in the current study, this relationship was not examined further.

In the current study, no association was found between sex and a likely presence of anxiety. In contrast, previous studies have reported that female sex is associated with higher anxiety [19, 30]. However, it was found that compared to breast cancer patients, patients with a prostate cancer diagnosis had lower odds of having a likely presence of anxiety and/or overall psychological distress. A study of 4,496 cancer patients with common cancer types (lung, brain, Hodgkin's lymphoma, pancreas, lymphoma, liver, head and neck, adenocarcinoma, breast, leukaemia, melanoma, colon, prostate and gynaecological) suggested that psychological distress prevalence varied by cancer type, with a trend towards prostate cancer patients having lower mean anxiety and depression scores than breast cancer patients [13]. It is possible that this finding by cancer type may be a surrogate for sex; however, more investigation of this is warranted.

The odds of a likely presence of depression were 3.3 times higher in respondents diagnosed with other common cancer types (including brain, colorectal, head and neck, lung, melanoma and non-Hodgkin's lymphoma) compared to respondents diagnosed with breast cancer. This is consistent with past findings indicating that patients diagnosed with some common and less common cancer types (e.g. lung cancer, brain cancer and pancreatic cancer) report high levels of distress [3, 13, 40].

Table 3 Multiple logistic regression analysis of demographic and disease characteristics of those with HADS classified likely presence of psychological distress

<table>
<thead>
<tr>
<th></th>
<th>Likely presence of psychological distress</th>
<th>Unadjusted OR (95 % CI)</th>
<th>Likelihood ratio chi² (df), p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (column %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>42 (25 %)</td>
<td>1</td>
<td>1 (3), p=0.8</td>
</tr>
<tr>
<td>Site 2</td>
<td>24 (18 %)</td>
<td>0.7 (0.4–1.2)</td>
<td>0.8 (0.4–1.4)</td>
</tr>
<tr>
<td>Site 3</td>
<td>19 (26 %)</td>
<td>1.0 (0.5–1.9)</td>
<td>1.0 (0.5–2.0)</td>
</tr>
<tr>
<td>Site 4</td>
<td>17 (20 %)</td>
<td>0.7 (0.4–1.4)</td>
<td>0.9 (0.5–1.8)</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–49</td>
<td>24 (26 %)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>32 (32 %)</td>
<td>1.4 (0.7–2.5)</td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>28 (19 %)</td>
<td>0.7 (0.3–1.2)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>18 (16 %)</td>
<td>0.5 (0.3–1.1)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45 (19 %)</td>
<td>1</td>
<td>29 (3), p&lt;0.001*</td>
</tr>
<tr>
<td>Female</td>
<td>57 (26 %)</td>
<td>1.5 (0.9–2.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer</td>
<td>30 (23 %)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>5 (5.0 %)</td>
<td>0.2 (0.07–0.5)</td>
<td>0.2 (0.06–0.5)</td>
</tr>
<tr>
<td>Other common cancer</td>
<td>41 (30 %)</td>
<td>1.4 (0.8–2.5)</td>
<td>1.4 (0.8–2.4)</td>
</tr>
<tr>
<td>Other or unknown cancer</td>
<td>26 (30 %)</td>
<td>1.5 (0.8–2.7)</td>
<td>1.4 (0.7–2.6)</td>
</tr>
</tbody>
</table>

Observations within each variable may not add to the total due to missing values

aIncludes brain cancer, colorectal cancer, head and neck cancer, lung cancer, and non-Hodgkin's lymphoma

bAssessed using the Hospital Anxiety and Depression Scale (HADS) total threshold score of ≥15
Acceptability of psychological screening within radiotherapy treatment centres

Radiotherapy treatment centre-based assessment of psychological distress appears to be both feasible and highly acceptable to patients. Consent rates to the current study were high and a large proportion of participants also indicated that they would be willing to complete additional touchscreen computer surveys in the same setting on future occasions.

Limitations

The HADS appears to be a sensitive instrument for screening purposes; however, the selection of threshold scores should be carefully considered [28]. The HADS is likely to provide a good indication of the likely presence of anxiety, depression and psychological distress among cancer outpatients, particularly when used in similar settings to previous studies applying the same threshold scores.

Selection of patients undergoing outpatient radiotherapy treatment is likely to have limited the current sample to well-functioning patients. There are a number of other disease variables which have been linked to mood outcomes in the past, including variables relating to current physical status [9]. These factors were not assessed in the current study, as any large variation in physical status is likely to have been screened out of the study by the selection of outpatients only.

Although a priori sample size and power calculations were undertaken, because the prevalence of depression was lower than anticipated, the study is likely to be underpowered to detect relationships between explanatory variables and this outcome. At least 800 participants would have been needed to detect differences of 20 % in characteristics between groups with 5 % significance level and 80 % power.

Implications

The likely presence of anxiety and depression was found to be slightly higher in this patient population compared to normative data from a non-clinical UK population using the same HADS threshold scores, where 13 % were identified with a likely presence of anxiety and 3.6 % with a likely presence of depression [41]. Since RT patients attend daily treatments and weekly treatment reviews, a window of opportunity exists for clinicians to intervene with patients in this setting [11]. Assessment of psychological distress in a radiotherapy treatment centre setting using touchscreen computers appears to be both feasible and acceptable to cancer patients.

The odds of a likely presence of anxiety, depression and overall psychological distress were found to differ by cancer type. This might reflect differences in prognosis, treatments or potentially in models of care. For instance, some cancer types are associated with worse side effects from radiotherapy treatment [42]. It has also been suggested that elevated levels of proinflammatory cytokines in some cancer types may be linked to higher rates of depression [43]. Alternatively, although tumour-specific nurse specialists or care coordinators are now available within institutions for more common cancer types, not all cancer types are routinely linked into a service such as this [44]. A limitation of this finding is that socio-demographic and medical predictor variables assessed in this study were all collected via patient self-report. Although self-reported data have been criticised for lacking accuracy as a result of recall biases [45], the accuracy of self-reported variables such as cancer type and time since diagnosis have been shown to be comparable with cancer registry data [33]. Future research should investigate in more detail these differences between cancer types.

Conclusions

This study provides information on the likely presence of anxiety and depression in a heterogeneous sample of cancer patients. The current findings partially support previous research suggesting an association between younger cancer patients and elevated levels of anxiety. Additionally, these findings also raise the question of how cancer type may influence a likely presence of anxiety, depression and psychological distress. Assessment of psychological distress in RT treatment centres appears to be acceptable to patients. RT settings hold promise for system-based identification and referral of oncology outpatients potentially affected by anxiety, depression and psychological distress.

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Conflict of interest No authors have reported financial relationships with research-sponsoring organisations. Ms Lisa Mackenzie, the corresponding author, had and has full control of the primary data. The authors agree to allow Supportive Care in Cancer to review the data, if requested.
References


35. Maher EJ, Mackenzie C, Young T, Marks D (1996) The use of the Hospital Anxiety and Depression Scale (HADS) and the EORTC QLQ-C30 questionnaires to screen for treatable unmet needs in...
Appendix 3.2: Statements of contribution from co-authors

Statement of contribution

I, Laureate Professor Rob Sanson-Fisher, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


14/08/2013
Laureate Professor Rob Sanson-Fisher (Co-Author) Date

16/08/2013
Ms Lisa Mackenzie (Candidate) Date

12/09/2013
Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

I, Dr Mariko Carey, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


15/8/2013

Dr Mariko Carey (Co-Author) Date

16/08/2013

Ms Lisa Mackenzie (Candidate) Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

I, Professor Catherine D’Este, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


15/8/2013

Professor Catherine D’Este (Co-Author) Date

16/8/2013

Ms Lisa Mackenzie (Candidate) Date

Professor John Rostas (Assistant Dean Research & Research Training) Date

12/09/2013
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Appendix 4: Paper Four

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Appendix 4.1: Published paper
Agreement between HADS classifications and single-item screening questions for anxiety and depression: a cross-sectional survey of cancer patients

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Background: We assessed agreement between reported anxiety and depression levels of cancer patients using (i) single self-report items and (ii) the Hospital Anxiety and Depression Scale (HADS). We also explored whether anxiety and depression assessment by (i) single self-report items or (ii) the HADS was most strongly associated with a preference to be offered professional assistance. The proportion of patients indicating that they would accept (or were currently using) professional support if they were experiencing anxiety or depression was also examined.

Patients and methods: A consecutive sample of cancer patients undergoing radiotherapy at four metropolitan public hospitals in Australia completed a touch screen computer survey. A consecutive subsample of patients attending three of these treatment centres answered additional questions about psychological support preferences.

Results: Of 304 respondents, 54% [95% confidence interval (CI) 48% to 60%) perceived that they were currently experiencing mild to severe anxiety and depression. 22% (95% CI 18% to 27%) indicated a preference to be offered professional help. There was moderate agreement between the HADS and single-item responses for categorisation of anxiety and depression. Patient-perceived mild to severe anxiety and depression levels appeared to be the best measure for identifying those with a preference to be offered professional assistance. Of a subsample of 193 respondents, 89% (95% CI 84% to 93%) indicated that if they were experiencing anxiety or depression, they would accept (or were currently using) professional support.

Conclusions: Single-item screening in a cancer care setting may not adequately capture clinical anxiety and depression. However, single-items assessing patients’ perceived levels of distress are useful indicators of whether patients want to be offered, and are likely to accept, psychosocial care.

Key words: anxiety, depression, HADS, oncology, questionnaire, single-item question

introduction

Psychosocial issues are under-recognised and under-treated in cancer patients [1, 2]. Resource efficient and effective methods of detection and treatment of psychosocial distress are needed. Ultra-short measures of anxiety and depression have potential to improve timely recognition of these conditions [3, 4].

Ultra-short measures such as the distress thermometer (DT) require patients to provide a numerical index of perceived distress [3, 5]. Ultra-short screening questions require patients to provide a yes or no response to single questions such as ‘Are you depressed?’ [4]. The DT and ultra-short screening questions have been found to have good ability to exclude non-cases (specificity), but a poorer ability to detect possible cases (sensitivity) [6, 7]. Increasing the number of response categories in single-item measures may help improve sensitivity [8]. We aimed to assess agreement between single-item measures asking patients to indicate their perceived level of (i) anxiety and (ii) depression, and similar categories recommended for the Hospital Anxiety and Depression Scale (HADS) [4, 8, 9]. Despite psychometric shortcomings [10, 11], the HADS is recommended for brief screening for anxiety and depression in oncology [9].

Cancer patients’ perception of their own level of anxiety and depression may impact on their uptake of psychosocial service referrals [2, 12–15]. We aimed to explore whether the HADS or patients’ perceived levels of distress provided the best indicator for identifying those with a preference to be offered professional help for anxiety and/or depression. We also describe the proportion of patients indicating that, if they were experiencing anxiety or depression, they would accept professional psychosocial support.
method

ethics approvals
Ethics approvals were obtained from the University of Newcastle and the New South Wales Population and Health Services Research Ethics Committees.

design and setting
A cross sectional survey was conducted at four radiation oncology treatment centres attached to metropolitan public hospitals in the Australian state of New South Wales. Each participating centres had a minimum of two linear accelerators available for radiotherapy, with average treatment throughput varying between 60 and 140 patients per day.

participants
Cancer patients attending radiotherapy appointments; aged 18 years or older; able to complete the survey in English; and able to give informed consent were eligible for the study.

procedure
A research assistant provided potential participants with written and verbal information about the study. Completion of the touch screen computer survey was taken as informed consent.

measures
The following were included in a larger survey examining perceptions of, and preferences for, patient-centred cancer care [16, 17].

participant demographic and medical characteristics. Participants reported their age, gender, postcode, region of birth, who they live with, when they were first diagnosed with cancer, if they had experienced a second cancer diagnosis or recurrence, most recent primary cancer diagnosis, and perceived aim of current treatment.

patients’ perceptions of their psychological distress. Participants were asked ‘What level of anxiety have you been experiencing in the last week?’ and ‘What level of depression have you been experiencing in the last week?’. Response options were ‘No anxiety; Mild anxiety; Moderate anxiety; or Severe anxiety’ and ‘No depression; Mild depression; Moderate depression; Severe depression’ respectively.

psychological distress. The HADS contains two 7-item subscales that measure depression (HADS-D) and anxiety (HADS-A) in the prior week. Scores were categorised as normal (0–7), mild (8–10), moderate (11–14), and severe (15–21) [18]. The characteristics of participants meeting HADS threshold scores are reported elsewhere [16].

preference to be offered professional support. Participants were asked: ‘Given your current levels of anxiety and/or depression; would you like to be offered some professional help?’ Those who responded ‘no’ were asked ‘Why don’t you want professional support for anxiety and/or depression?’

willingness to accept professional help for anxiety or depression. A subsample of consecutive patients attending the first three participating treatment centres were asked ‘If you were experiencing anxiety or depression; would you accept the following types of professional help?’ in reference to: group counselling at the cancer centre; individual counselling at the cancer centre; treatment/counselling from my cancer doctor; group counselling outside the cancer centre; individual counselling outside the cancer centre; treatment/counselling from my GP; internet (online) support. All support types were listed on a single-question screen in a matrix format, with the response options: (i) no, definitely not; (ii) no, probably not; (iii) yes, probably; and (iv) yes, currently using.

statistical analysis

agreement between HADS and patients. Agreement between HADS categories (normal, mild, moderate, and severe) [18] and self-classification of anxiety and depression (none, mild, moderate, and severe) was assessed using weighted k (bias adjusted), with bootstrapping techniques to estimate 95% confidence intervals (95% CIs). The Stuart–Maxwell test for marginal homogeneity was used to assess whether cancer patients tend to self-rate their anxiety or depression higher or lower than the HADS ratings.

indicators of a preference for being offered support. Univariate logistic regression analyses were used to identify factors associated with a preference to be offered professional support. Variables included: age category; sex; country of birth; cancer type; perceived treatment aim, anxiety, and depression. Variables with a P value of ≤0.2 were included in four separate non-nested multiple logistic regression models. Each model included one of the four different anxiety and depression terms (see supplementary File S1, available at Annals of Oncology online for description of terms a-d). Recruitment site was included as an adjustment for the sampling strategy. The backward stepwise method was used to remove variables with a P value of ≥0.1 on the likelihood ratio test. To ensure comparability of models, any explanatory variable retained in the final model was included in all models. Odds ratios with 95% CIs are reported. The most appropriate measure for investigating the relationship with preference for professional support was assessed by: (i) the amount of missing data; (ii) the significance of the likelihood ratio test terms in the models; (iii) the Hosmer–Lemeshow goodness of fit measure; and (iv) the relative fit of the models using the Akaike Information Criterion (AIC).

willingness to accept support. The proportion of patients with a willingness to accept professional support for anxiety and depression is reported with 95% CIs. See supplementary File S1, available at Annals of Oncology online for detail of analyses.

See supplementary File S2, available at Annals of Oncology online for sample size calculations. All analyses were conducted using Stata version 11.2 (StataCorp, TX), applying a significance level of 5%.

results
Of 529 patients screened for inclusion in the study, 98 were excluded due to: insufficient English proficiency (n = 45); not currently receiving radiotherapy (n = 29); already having been approached about the survey (n = 6); clinic staff concern about patient burden or capacity to give informed consent (n = 3); being under the age of 18 (n = 2); not having a cancer diagnosis (n = 1) or an unspecified reason (n = 12). Of the 431 eligible patients, 369 consented (86%) and 304 (71%) completed the survey. Non-completion was typically due to patients having insufficient time before their treatment appointment. Only surveys with complete data are included in the analyses. On average, respondents were 61.6 years old (SD = 13.8, minimum = 18.9, maximum = 91.4). Additional sample characteristics are in Table 1.
agreement between patients’ perceptions and HADS classifications

One hundred and sixty-four participants (54%, 95% CI 48% to 60%) perceived that they were experiencing mild to severe anxiety or depression. Tables 2 and 3 provide the numbers of patients with each self-perceived and HADS level of anxiety and depression, respectively.

Table 2 indicates the level of agreement between HADS anxiety classifications and patients’ self-reported levels. The observed proportion of agreement was 93%, with weighted $\kappa$ of 0.5 (95% CI 0.4 to 0.6) indicating moderate agreement between patients’ perceptions and the HADS ($P < 0.0001$). The Stuart–Maxwell test of marginal homogeneity was significant [$\chi^2 (3) = 49, P < 0.0001$]; patients generally reported higher levels of anxiety than was indicated by HADS-A classification levels (see Table 2).

Table 3 shows the level of agreement between HADS depression classifications and patients’ self-reported levels. The observed proportion of agreement was 95%, with weighted $\kappa$ of 0.5 (95% CI 0.4 to 0.6) indicating moderate agreement ($P < 0.0001$). The Stuart–Maxwell test of marginal homogeneity was significant ($\chi^2 (3) = 30, P < 0.0001$); patients generally reported higher levels of depression than what was determined from their HADS-D score (see Table 3).

**patient preference to be offered professional support**

Sixty-seven participants expressed a preference to be offered professional support for their anxiety and/or depression (22%, 95% CI 18% to 27%). Of these, 51% ($n = 34$, 95% CI 38% to 63%) met HADS threshold scores for mild to severe anxiety and/or depression. Reasons for preferring not to be offered support are presented in supplementary File S3, available at Annals of Oncology online. These findings suggest that self-reported anxiety and depression levels may better predict a preference to be offered professional support than HADS classifications.

---

**Table 1.** Characteristics of the sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Overall sample ($N = 304$)</th>
<th>Support preferences subsample ($N = 193$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td>Males</td>
<td>158 (52)</td>
<td>99 (51)</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–49</td>
<td>64 (21)</td>
<td>39 (20)</td>
</tr>
<tr>
<td>50–59</td>
<td>58 (19)</td>
<td>34 (18)</td>
</tr>
<tr>
<td>60–69</td>
<td>99 (33)</td>
<td>62 (32)</td>
</tr>
<tr>
<td>70+</td>
<td>83 (27)</td>
<td>58 (30)</td>
</tr>
<tr>
<td>Australian born</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband/wife/partner</td>
<td>187 (62)</td>
<td>119 (62)</td>
</tr>
<tr>
<td>Children/step-children</td>
<td>65 (21)</td>
<td>42 (22)</td>
</tr>
<tr>
<td>Other family</td>
<td>22 (7.2)</td>
<td>12 (6.2)</td>
</tr>
<tr>
<td>Friend/s</td>
<td>8 (2.6)</td>
<td>6 (3.1)</td>
</tr>
<tr>
<td>Unrelated flatmate/co-tenant</td>
<td>4 (1.3)</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td>Living alone</td>
<td>62 (20)</td>
<td>38 (20)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>77 (25)</td>
<td>53 (27)</td>
</tr>
<tr>
<td>Prostate</td>
<td>68 (22)</td>
<td>44 (23)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>31 (10)</td>
<td>17 (8.8)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>17 (5.5)</td>
<td>9 (4.7)</td>
</tr>
<tr>
<td>Lung</td>
<td>16 (5.3)</td>
<td>8 (4.1)</td>
</tr>
<tr>
<td>Brain</td>
<td>12 (3.9)</td>
<td>8 (4.1)</td>
</tr>
<tr>
<td>Non-Hodgkin’s lymphoma</td>
<td>11 (3.6)</td>
<td>7 (3.6)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>10 (3.3)</td>
<td>5 (2.6)</td>
</tr>
<tr>
<td>Other</td>
<td>56 (18)</td>
<td>38 (20)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (2.0)</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td>48 (16)</td>
<td>35 (19)</td>
</tr>
<tr>
<td>Second diagnosis or recurrence</td>
<td>93 (32)</td>
<td>59 (32)</td>
</tr>
<tr>
<td>Hospital site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1</td>
<td>62 (20)</td>
<td>62 (32)</td>
</tr>
<tr>
<td>Site 2</td>
<td>83 (27)</td>
<td>83 (43)</td>
</tr>
<tr>
<td>Site 3</td>
<td>75 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Site 4</td>
<td>84 (28)</td>
<td>48 (25)</td>
</tr>
<tr>
<td>Number of outpatient clinic appointments</td>
<td>Median (Q1, Q3)</td>
<td>Median (Q1, Q3)</td>
</tr>
<tr>
<td>Number of radiotherapy treatment appointments</td>
<td>8 (3, 16)</td>
<td>7 (3, 15)</td>
</tr>
<tr>
<td>Weeks since diagnosis</td>
<td>28.2 (15.9, 69.0)</td>
<td>29.2 (15.9, 74.1)</td>
</tr>
</tbody>
</table>

Due to missing values, non-mutually exclusive categories and rounding, numbers for some variables may not add to total sample size.

---

**Table 2.** Number and percentage of patients whose HADS anxiety levels agree with their perceived anxiety levels

<table>
<thead>
<tr>
<th>Perceived level of anxiety</th>
<th>HADS-A classification</th>
<th>Moderate anxiety</th>
<th>Severe anxiety</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No anxiety</td>
<td>138 (90%)</td>
<td>14</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Mild anxiety</td>
<td>62 (42%)</td>
<td>21 (21%)</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>Moderate anxiety</td>
<td>16 (10%)</td>
<td>18 (36%)</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Severe anxiety</td>
<td>0 (0%)</td>
<td>1 (50%)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>216</td>
<td>45</td>
<td>35</td>
<td>8</td>
</tr>
</tbody>
</table>
Table 3. Number and percentage of patients whose HADS depression levels agree with their perceived depression levels

<table>
<thead>
<tr>
<th>Perceived level of depression</th>
<th>HADS-D classification</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Normal</td>
<td>Mild</td>
</tr>
<tr>
<td>No depression</td>
<td>195 (93%)</td>
<td>13</td>
</tr>
<tr>
<td>Mild depression</td>
<td>46 (23%)</td>
<td>15</td>
</tr>
<tr>
<td>Moderate depression</td>
<td>9 (31%)</td>
<td>10</td>
</tr>
<tr>
<td>Severe depression</td>
<td>1 (0%)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>251</td>
<td>38</td>
</tr>
</tbody>
</table>

Table 4 presents the results of the univariate analysis for all included variables, and the multivariate analysis of models a–d (see supplementary File S1, available at Annals of Oncology online, for description of terms a–d). The full number of observations (n = 304) was available for all models. In models a–d, patients classified with anxiety had significantly higher odds of a preference to be offered professional support for current anxiety and/or depression. In model c, patients classified with depression had significantly higher odds of a preference to be offered professional support for current anxiety and/or depression. This was not the case for models a, b, and d. The Hosmer–Lemeshow test results indicated that all models fit the data well. The relative fit of the models using the AIC indicated that model c was marginally the strongest model, followed by model d, a; and b. Based on the specified criteria, model c (patient-perceived mild–severe anxiety and depression) has the strongest association with a patient preference to be offered professional support for current anxiety and/or depression. Patients’ perceived level or severity of anxiety and depression is likely to be an important factor in determining referral uptake.

The findings from this study pose two dilemmas for psychosocial service delivery in oncology settings: how can we ensure that those experiencing clinical levels of anxiety and depression are provided with appropriate services; and what sorts of services should be delivered to those with perceived anxiety or depression which does not reach ‘threshold’ levels according to the HADS?

If psychosocial resources are limited, there may be a need to prioritise specialised services so that they reach those with clinically significant levels of anxiety and depression. Respondents indicated that individual support methods were considered to be more acceptable than group and online support, and support provided at the cancer centre was more acceptable than support provided external to the cancer centre (supplementary File S4, available at Annals of Oncology online). Lower intensity and cost self-help strategies have been found beneficial in reducing the symptom burden in individuals with ‘sub-threshold’ depression and may be appropriate for those reporting self-perceived, but not clinically significant, anxiety and depression. This approach has been recommended in stepped-care models of psychosocial care [15]. As older adults had lower odds of endorsing group and online strategies (supplementary File S5, available at Annals of Oncology online), these potentially cost-effective interventions may be better suited to younger cancer patients.

For those who are identified as at-risk by the HADS but who do not self-report elevated anxiety or depression, it is important to determine whether the symptoms identified by the HADS are due to other causes. If these symptoms interfere with the patients’ functioning, then the potential benefits of seeking evidence-based treatments should be discussed [3].

These findings may be a cause to reconsider how screening can be best used to provide patient-centred cancer care [12, 20, 21].
Table 4. Likelihood ratio (LR) univariate and multiple logistic regression results from four logistic regression models of the outcome ‘current preference to be offered professional support for anxiety and/or depression’ (N = 304)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Desire to be offered professional support, n (row %)</th>
<th>Multiple logistic regression Model a: HADS mild–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model b: HADS moderate–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model c: Patient perceived mild–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model d: Patient perceived moderate–severe anxiety and/or depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td></td>
<td>LR $\chi^2$ (df), $P$ unadjusted OR (95% CI)</td>
<td>LR $\chi^2$ (df), $P$ adjusted OR (95% CI)</td>
<td>LR $\chi^2$ (df), $P$ adjusted OR (95% CI)</td>
<td>LR $\chi^2$ (df), $P$ adjusted OR (95% CI)</td>
</tr>
<tr>
<td>Site 1</td>
<td>30.6 (3), $P &lt; 0.0001^e$</td>
<td>33.4 (3), $P &lt; 0.0001^e$</td>
<td>30.4 (3), $P &lt; 0.0001^e$</td>
<td>31.1 (3), $P &lt; 0.0001^e$</td>
<td>30.6 (3), $P &lt; 0.0001^e$</td>
</tr>
<tr>
<td>Site 2</td>
<td>28 (34)</td>
<td>0.9 (0.4–1.7)</td>
<td>0.8 (0.4–1.7)</td>
<td>0.8 (0.4–1.7)</td>
<td>0.8 (0.4–1.7)</td>
</tr>
<tr>
<td>Site 3</td>
<td>10 (13)</td>
<td>0.3 (0.1–0.6)</td>
<td>0.2 (0.1–0.6)</td>
<td>0.3 (0.1–0.6)</td>
<td>0.2 (0.1–0.6)</td>
</tr>
<tr>
<td>Site 4</td>
<td>6 (7)</td>
<td>0.1 (0.05–0.3)</td>
<td>0.1 (0.05–0.3)</td>
<td>0.1 (0.05–0.4)</td>
<td>0.1 (0.04–0.3)</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td>0.2 (3), $P = 0.9780$</td>
<td>0.1 (1), $P = 0.8199$</td>
<td>1.4 (1), $P = 0.2307^d$</td>
<td>1.2 (1), $P = 0.2706^d$</td>
</tr>
<tr>
<td>18–49</td>
<td>15 (23)</td>
<td>1</td>
<td>1</td>
<td>1.0 (1), $P = 0.3211^d$</td>
<td>1.0 (1), $P = 0.3211^d$</td>
</tr>
<tr>
<td>50–59</td>
<td>13 (19)</td>
<td>0.9 (0.4–2.2)</td>
<td>1.5 (0.8–2.8)</td>
<td>1.0 (1), $P = 0.3211^d$</td>
<td>1.0 (1), $P = 0.3211^d$</td>
</tr>
<tr>
<td>60–69</td>
<td>22 (33)</td>
<td>0.9 (0.4–2.0)</td>
<td>1.6 (0.8–2.9)</td>
<td>1.4 (0.8–2.7)</td>
<td>1.4 (0.8–2.7)</td>
</tr>
<tr>
<td>70+</td>
<td>17 (25)</td>
<td>0.8 (0.4–1.8)</td>
<td>1.6 (1), $P = 0.2126^d$</td>
<td>1.2 (1), $P = 0.2733^d$</td>
<td>0.9 (1), $P = 0.3342^d$</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td>0.1 (1), $P = 0.8199$</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Male</td>
<td>34 (22)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>33 (23)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Australian born</td>
<td></td>
<td>2.6 (1), $P = 0.1100^c$</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>39 (19)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>28 (27)</td>
<td>1.6 (0.9–2.8)</td>
<td>1.5 (0.8–2.8)</td>
<td>1.4 (0.8–2.7)</td>
<td>1.4 (0.8–2.7)</td>
</tr>
<tr>
<td>Perceived palliative treatment aim</td>
<td></td>
<td>2.1 (1), $P = 0.1463^c$</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>48 (20)</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Yes</td>
<td>14 (29)</td>
<td>1.7 (0.8–3.4)</td>
<td>1.6 (0.8–3.5)</td>
<td>1.6 (0.8–3.5)</td>
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<td>Cancer type</td>
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<td>1</td>
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<td>Breast</td>
<td>19 (25)</td>
<td>0.6 (0.3–1.3)</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>Prostate</td>
<td>11 (16)</td>
<td>0.9 (0.5–1.7)</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>Other</td>
<td>37 (23)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>HADS mild–severe anxiety</td>
<td></td>
<td>6.6 (1), $P = 0.0104^e$</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<tr>
<td>No</td>
<td>39 (18)</td>
<td>2.1 (1.2–3.7)</td>
<td>2.7 (1.4–5.4)</td>
<td>2.7 (1.4–5.4)</td>
<td>2.7 (1.4–5.4)</td>
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<td>Yes</td>
<td>28 (32)</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>HADS mild–severe depression</td>
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<td>2.3 (1), $P = 0.1262^e$</td>
<td>0.01 (1), $P = 0.9214$</td>
<td>1</td>
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<td>Yes</td>
<td>16 (30)</td>
<td>1.7 (0.9–3.3)</td>
<td>1.0 (0.4–2.1)</td>
<td>1.0 (0.4–2.1)</td>
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<td>HADS moderate–severe anxiety</td>
<td></td>
<td>8.0 (1), $P = 0.0048^e$</td>
<td>6.8 (1), $P = 0.0089^e$</td>
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<td>50 (19)</td>
<td>1</td>
<td>1</td>
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<td>Yes</td>
<td>17 (40)</td>
<td>2.8 (1.4–5.5)</td>
<td>2.9 (1.3–6.5)</td>
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<th>Variables</th>
<th>Desire to be offered professional support, ( n ) (row %)</th>
<th>Univariate logistic regression</th>
<th>Multiple logistic regression Model a: HADS mild–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model b: HADS moderate–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model c: Patient perceived mild–severe anxiety and/or depression</th>
<th>Multiple logistic regression Model d: Patient perceived moderate–severe anxiety and/or depression</th>
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<td>HADS moderate–severe depression(^b)</td>
<td></td>
<td>1.1 (1), ( P = 0.3020^c )</td>
<td>0.00 (1), ( P = 0.9512 )</td>
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<td>No</td>
<td>62 (21)</td>
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<td>1 (0.3–3.5)</td>
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<td>Yes</td>
<td>5 (33)</td>
<td>1.8 (0.6–5.6)</td>
<td>1</td>
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<td>Perceived mild–severe anxiety</td>
<td></td>
<td>17.0 (1), ( P &lt; 0.0001^c )</td>
<td>5.4 (1), ( P = 0.0199^e )</td>
<td></td>
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<td>1</td>
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<td>Yes</td>
<td>48 (32)</td>
<td>3.3 (1.8–5.9)</td>
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<td>2.3 (1.1–4.6)</td>
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<tr>
<td>Perceived mild–severe depression</td>
<td></td>
<td>16.7 (1), ( P &lt; 0.0001^c )</td>
<td>6.4 (1), ( P = 0.0116^e )</td>
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<td>No</td>
<td>32 (15)</td>
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<td>1</td>
<td>1</td>
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<tr>
<td>Yes</td>
<td>35 (37)</td>
<td>3.2 (1.8–5.7)</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Perceived moderate–severe anxiety</td>
<td></td>
<td>15.9 (1), ( P = 0.0001^c )</td>
<td>7.7 (1), ( P = 0.0054^e )</td>
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<td>No</td>
<td>44 (17)</td>
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<td>1</td>
<td>3.4 (1.5–7.8)</td>
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<td>Yes</td>
<td>23 (44)</td>
<td>3.7 (2.0–7.1)</td>
<td>1</td>
<td>1</td>
<td>3.4 (1.5–7.8)</td>
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<td>Perceived moderate–severe depression</td>
<td></td>
<td>15.9 (1), ( P = 0.0001^c )</td>
<td>2.2 (1), ( P = 0.1372 )</td>
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<td>16 (53)</td>
<td>5.0 (2.3–10.9)</td>
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<td>1</td>
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<tr>
<td>Hosmer–Lemeshow goodness of fit</td>
<td></td>
<td>Hosmer–Lemeshow ( \chi^2 ) (7) = 9.7, ( P = 0.2092 )</td>
<td>Hosmer–Lemeshow ( \chi^2 ) (4) = 3.0, ( P = 0.5557 )</td>
<td>Hosmer–Lemeshow ( \chi^2 ) (8) = 9.4, ( P = 0.3134 )</td>
<td>Hosmer–Lemeshow ( \chi^2 ) (4) = 2.1, ( P = 0.7119 )</td>
<td></td>
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<tr>
<td>AIC (df = 6) = 292</td>
<td></td>
<td>AIC (df = 6) = 294</td>
<td>AIC (df = 6) = 279</td>
<td>AIC (df = 6) = 281</td>
<td></td>
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</tbody>
</table>

Observations within each variable may not add to the total due to missing values.

\(^a\)Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types.

\(^b\)Assessed using the Hospital Anxiety and Depression Scale (HADS).

\(^c\)Included in the initial multiple logistic regression model.

\(^d\)Eliminated during backwards stepwise multiple logistic regression analysis.

\(^e\)Significant.
Combining ultra-short screening with an assessment of preference to be offered psychological support may allow the detection of patients who may benefit from some form of psychosocial intervention. However, screening instruments and clinical judgement remain crucial for identifying potentially vulnerable patients who may not have insight into the severity of their emotional distress. The implications of considering patients’ perceived distress and preferences for support, rather than relying solely on screening and clinical diagnosis, should be explored. Future research could assess links between patients’ preferences for psychological support and outcomes such as uptake and effectiveness of support services.

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disclosure
The authors have declared no conflicts of interest.

references
1. Butz BD, Johansen C. Screening for distress, the 6th vital sign: where are we, and where are we going? Psychooncology 2011; 20: 569–571.
Appendix 4.2: Statements of contribution from co-authors

Statement of contribution

I, Laureate Professor Rob Sanson-Fisher, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


14/08/2013
Laureate Professor Rob Sanson-Fisher (Co-Author)  Date

16/08/2013
Ms Lisa Mackenzie (Candidate)  Date

12/09/2013
Professor John Rostas (Assistant Dean Research & Research Training)  Date
Statement of contribution

I, Ms Sze Lin Yoong, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


13/08/2013

Ms Sze Lin Yoong (Co-Author)
Date

13/08/2013

Ms Lisa Mackenzie (Candidate)
Date

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training)
Date
Statement of contribution

I, Dr Mariko Carey, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


15/8/2013

Dr Mariko Carey (Co-Author) Date

16/08/2013

Ms Lisa Mackenzie (Candidate) Date

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I, Professor Catherine D’Este, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


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Ms Lisa Mackenzie (Candidate)  Date

Professor John Rostas (Assistant Dean Research & Research Training)  Date

12/09/2013
Statement of contribution

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13/08/2013

Ms Lisa Mackenzie (Candidate)  Date

12/09/2013

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Appendix 5: Paper Five

Permission to copy and communicate this work, “Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey”, has been kindly granted by BMJ Publishing Group.
Appendix 5.1: Published paper
Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey

Lisa J Mackenzie,1,2 Rob W Sanson-Fisher,1,2 Mariko L Carey,1,2 Catherine A D’Este2,3,4

ABSTRACT
Objectives: We aimed to describe the proportion and characteristics of cancer patients who perceived that better care would have greatly improved their well-being in (1) specific and (2) multiple domains of patient-centred care.

Design: Cross-sectional touchscreen computer survey.

Setting: Four Australian radiation therapy departments located within major urban public hospitals.

Participants: Radiation therapy outpatients were invited to participate in a touchscreen computer survey. Eligible patients were at least 18 years old, diagnosed with cancer and had sufficient English to complete the survey.

Primary outcome measure: Participants were asked whether their well-being could have been greatly improved if better care had been provided across eight domains of patient-centred care. Characteristics of those respondents who identified (1) specific and (2) multiple domains where it was perceived that better care would have greatly improved their well-being were examined.

Results: Of 508 eligible radiation therapy patients, 344 (68%) completed the survey. Patients most frequently perceived that better care in the following domains could have improved their well-being: information and communication about their cancer (22%; 95% CI 18% to 27%); emotional and spiritual support (22%; 95% CI 18% to 27%); management of physical symptoms (21%; 95% CI 17% to 26%); and involvement of friends and family (21%; 95% CI 17% to 26%). Just under one-third of respondents (31%; 95% CI 26% to 36%) indicated that their well-being could have been improved by better care across two or more domains of care. Patients in younger age groups and migrants to Australia had higher odds of endorsing multiple domains where better care would have improved their well-being.

Conclusions: Further investigation of patients’ perceptions of how their perceived quality of care might be improved is warranted, particularly among patients in younger age groups and migrants to Australia.

INTRODUCTION
Why assess patient views of quality of care?

The Institute of Medicine (IOM) in the USA, an independent organisation for gathering evidence to assist health decision-making, has indicated the urgency of assessing and improving the quality of healthcare.1 Quality healthcare is care that is safe, timely, effective, efficient, equitable and patient-centred.2 A patient-centred approach to care is defined as being respectful of, and responsive to, patients’ physical, social and emotional preferences and needs.3 Provision of patient-centred care may contribute to
improvements in patients’ physical, mental and social well-being. A patient-centred approach to care is now endorsed as a key component of quality healthcare by many organisations (including the WHO) and governments (eg, in Australia, the USA, the UK, Canada, Germany, France, the Netherlands and Switzerland). Although quality of care is often examined through audit and benchmarking of clinical outcomes data, examining patients’ judgements of how their experiences of care correspond with their preferences and needs is required in order to assess the quality of patient-centred care.

What has previous patient-centred care research contributed to knowledge about prioritising quality improvement efforts?

Quality of patient-centred care has been assessed using a variety of patient-reported outcome measures including surveys of patient satisfaction and experiences which are closely linked to the IOM patient-centred care conceptual framework. Patient satisfaction surveys have been criticised because responses may be heavily dependent upon patients’ expectations of care, leading to the development of patient experience surveys. The Picker Institute survey assesses outpatients’ experiences of care across the domains of patients’ preferences; emotional support; physical comfort; information and education; coordination of care; access to care and involvement of family/friends. Recently, indicators of the quality of patient-centred care have been developed from international patient-centred oncology clinical practice guidelines. These indicators have been grouped across the domains of information; coordination/organisation of care; physical support; emotional and psychological support; communication and respect; involvement; access and follow-up/after-care. To date, these approaches have not attempted to capture patient perceptions of the degree to which their well-being would benefit from improved care across these different domains. Drawing upon the formal supportive care needs assessment approach which aims to identify the level of patient need for help, identification of patients’ views of the relative benefit that would be conferred by improvements in different patient-centred domains care may assist with identifying and prioritising quality improvement efforts.

Some subgroups of patients may perceive that they receive poorer care than others. For instance, older patients may be more likely than younger patients to express satisfaction with care, possibly relating to differences in the expectations for care provision. Additionally, cancer patients who have clinically significant levels of anxiety have been found to give lower ratings of satisfaction with care. Well-being in patients diagnosed with chronic illness may be linked to aspects of social support such as having a partner, and also potentially to ethnicity. Given that there is some evidence of increased psychological distress and supportive care needs prior to and during cancer treatment, it may also be that treatment stage may impact on perceptions of care.

Patient-centred care for radiation therapy patients

It is recommended that approximately 50% of cancer patients undergo radiation therapy (RT) treatment. Given that this treatment is often characterised by frequent contact with the healthcare system over the course of treatment, the RT setting provides an opportunity for addressing patient perceived needs across the multiple domains of patient-centred care. Although research into specific domains and specific cancer types has been conducted in radiotherapy settings, to the best of our knowledge, this is the first study to ask cancer patients undergoing RT about their perceptions of how better care across multiple patient-centred domains could improve their well-being. Further, no previous studies have identified characteristics of RT patients who are likely to perceive better patient-centred care.

This study aimed to examine the proportion and characteristics of RT patients who indicate that their well-being could have been greatly improved by better cancer care across each of eight domains of patient-centred care. We also aimed to assess characteristics associated with patient perception that better care across multiple domains of patient-centred care would have improved their well-being.

METHODS

Ethics approvals

Ethics approval was obtained from the University of Newcastle and NSW Population & Health Services Research Ethics Committees.

Design

A cross-sectional survey was completed using touchscreen computers.

Participants

Radiation oncology outpatients were recruited from four RT departments in a major urban centre in Australia between March and December 2010. Each RT department was attached to a major public teaching hospital, and had at least three Linear Accelerators available for treatment. Eligible patients were aged 18 years or older, diagnosed with cancer and had sufficient command of English to complete the touchscreen computer survey. Patients who were receiving both radical and palliative treatment were eligible. Those who were attending the clinic for the first time or who were considered by the clinic staff to be too unwell or unable to give informed consent were excluded.

Procedure

Patients waiting for RT treatment were invited to participate in the study by a research assistant. Consenting
patients were given a unique identification code to login to the touchscreen computer questionnaire. If patients were called into their treatment before finishing their survey, they had the option of resuming after their treatment. Touchscreen computer surveys have been reported as being faster and easier to use for outpatients than pencil and paper surveys, and have been found to be acceptable to oncology patients.

**Measures**

Digivey survey software (CREOSO—Digivey Survey Center, Phoenix, Arizona) was used to programme the patient survey, which was administered using Dell Latitude XT2 touchscreen laptop computers.

**Quality of care: patient-centred care**

Questions and domain descriptions were developed to correspond with domains of patient-centred care described in the literature, ensuring face validity of the items and clinical relevance to patients currently undergoing treatment. Survey items were extensively pilot tested and modified based on feedback from 67 patients. Eight items, each assessing a different domain of care, were presented on separate screens with the stem, ‘During my cancer care, my well-being would have been greatly improved by.’ Table 1 lists the eight items and a short description of each domain that was presented at the bottom of the touchscreen. Patients were asked to indicate their level of agreement with each statement on a four-point Likert scale (Strongly disagree, Disagree, Agree, Strongly agree). Internal consistency of the items was assessed using Cronbach’s α.

**Table 1** Survey items and descriptions (each assessing a different domain of care)

<table>
<thead>
<tr>
<th>Item</th>
<th>On screen description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better management of my physical symptoms</td>
<td>May relate to your pain, sleeplessness, other side-effects and symptoms</td>
</tr>
<tr>
<td>Better information and communication about my cancer and care</td>
<td>May include: clear and consistent information about your diagnosis, test results, treatment, taking medications, food you should be eating, exercise you can do safely, etc</td>
</tr>
<tr>
<td>Better emotional and/or spiritual support</td>
<td>May include services or support to help you cope with: the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body images, etc</td>
</tr>
<tr>
<td>Better services, information and support for my friends/family</td>
<td>May include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care</td>
</tr>
<tr>
<td>Better staff approachability and respect for me</td>
<td>Describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions</td>
</tr>
<tr>
<td>Getting better access to the care I need when required</td>
<td>Describes not having to wait too long to get appointments, and having treatment and medical advice available when needed</td>
</tr>
<tr>
<td>Better services/support to cope with changes to my relationships</td>
<td>May include: knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships</td>
</tr>
<tr>
<td>Better services/advice to assist me with practical concerns</td>
<td>May include being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues</td>
</tr>
</tbody>
</table>

**Demographic characteristics**

Patient self-report was used to collect age, gender, whether participants were born in Australia, living with a partner and the postcode of participants’ usual place of residence.

**Disease characteristics**

A multiple choice question, ‘What is your most recent primary cancer diagnosis?’ was used to determine respondents’ most recent primary cancer diagnosis. Common cancer types were listed on screen, along with the categories ‘other’—please specify and ‘don’t know’. Approximate time since diagnosis was calculated from the patient’s self-reported year and month of diagnosis and their recruitment date. Patients were asked to indicate the number of RT treatment and outpatient appointments they had attended; whether they had experienced a second diagnosis and/or recurrence; and whether they perceived that the aim of their treatment was to cure the cancer, prevent the cancer from coming back or control symptoms of cancer (cure is not possible).

**Psychological characteristics**

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-report measure of anxiety and depression. Both the anxiety and depression subscales provide scores of between 0 and 21 where 0–7=Normal; 8–10=Mild; 11–14=Moderate; 15–21=Severe. The scale has been utilised in research and in clinical practice, with demonstrated reliability and validity. HADS scores have been found to be comparable when administered by touchscreen computer and pen-and-paper in a population of patients with cancer.
Patient-centred cancer care

Statistical methods

RT patients were defined as having endorsed each domain if they indicated that they ‘agreed’ or ‘strongly agreed’ that better care would have greatly improved their well-being. The proportion of patients endorsing each domain was reported with 95% CIs. Respondents were then dichotomised on the basis of: (1) 0–1 domains endorsed or (2) multiple (2 or more) domains endorsed. Univariate logistic analysis was used to investigate the relationship between demographic characteristics, disease factors and psychological distress and patient endorsement of (1) each of the eight domains of care and (2) multiple (2 or more) domains of care requiring improvement. The explanatory variables examined included age (18–49, 50–59, 60–69, 70 plus), sex (male, female), cancer diagnosis (Breast, Prostate, Other/Don’t Know), second diagnosis and/or recurrence (no, yes), Australian-born (no, yes), living with a partner (no, yes), anxiety (no, yes), depression (no, yes), usual place of residence (urban/rural, based on the Accessibility/Remoteness Index of Australia (ARIA+) score), socio-economic status (SES) (Socio-Economic Indexes for Areas average scores34) and the number of radiotherapy treatment appointments attended (continuous measure). Variables with a p value of 0.2 or less on the univariate likelihood ratio test were included in the multiple logistic regression model. The backwards stepwise method was then used to remove all variables with a p value of 0.1 or more on the likelihood ratio test, with the recruitment site included in all multiple regression models. The fit of the final model was assessed using the Hosmer-Lemeshow goodness of fit test. For individual domains, ORs with 95% CIs are reported for multiple regression models. For the assessment of characteristics associated with endorsing multiple domains, ORs with 95% CIs are reported for univariate and multiple regression models. Analysis was conducted using STATA V.11.2, and a significance level of 0.05 was used.

Sample size and statistical power

We aimed to recruit a total of 450 patients which, based on 50% of patients perceiving the need for better care in each domain, would allow us to obtain prevalence estimates with 95% CIs within ±5% of the point estimate. This sample size would also be sufficient to detect differences of approximately 15% in characteristics between those who perceive the need for better care in each individual domain and also multiple domains of care with 80% power and 5% significance level.

RESULTS

Of the 639 patients screened for eligibility, 110 were ineligible due to: inadequate English (n=51); not currently receiving RT (n=32); had already been approached about the study (n=6); not being diagnosed with cancer (n=3); clinic staff concern about patient burden or ability to give informed consent (n=3); being aged under 18 (n=2) or no specified reason (n=13). Of the 529 eligible patients, 85% (n=451) consented and 69% (n=365) completed the survey. Incomplete surveys were primarily because patients were called into their treatment appointment before survey completion, and no data were available from these surveys. An additional 21 patients were excluded because they reported that they were attending their first RT treatment. Once these participants were ruled ineligible, the overall response rate was 68% of 508 eligible RT patients. Table 2 shows the characteristics of the 344 respondents. 51% were men, the median age was 63.3 (Quarter (Q) 1: 52.2, Q3: 70.5) and the median number of weeks since diagnosis was 27.6 (Q1: 16.0, Q3: 57.3). The majority of respondents (97%) were currently receiving RT treatment, with the remainder reporting that they were attending the treatment centre for a check-up. The distribution of primary cancer type within the sample can be seen in table 2.

Internal consistency of items

When considering the items with responses on a four-point Likert scale, the internal consistency (Cronbach’s α) was 0.92. When the responses were dichotomised (agree vs disagree), Cronbach’s α was 0.89.

| Table 2 Demographic and disease characteristics of respondents (n=344) |
|---------------------------------|-----------------|----------------|
| Characteristic                  | Mean (min, max) |
| Age (years)                     | 61.4 (18.9–91.4) |
| Males                           | 176 (51%) |
| Region of birth                 |                |
| Australia                       | 231 (67%) |
| UK/Ireland                      | 30 (8.7%) |
| Europe                          | 29 (8.4%) |
| Asia                            | 25 (7.2%) |
| Other                           | 29 (8.4%) |
| Perceived palliative treatment aim | 46 (14%) |
| Primary cancer type             |                |
| Breast                          | 93 (27%) |
| Prostate                        | 73 (21%) |
| Head and neck                   | 33 (9.6%) |
| Colorectal                      | 20 (5.8%) |
| Brain                           | 15 (4.4%) |
| Lung                            | 15 (4.4%) |
| Other                           | 89 (26%) |
| Don’t know                      | 06 (1.7%) |
| Second diagnosis/recurrence     | 96 (28%) |
| Completed appointments with cancer doctor | 3 (2, 5) |
| Completed radiation therapy     | 9 (4, 17) |
| appointments                    |                |
| Weeks since diagnosis           | 27.6 (16, 37.3) |

Note: Observations within each variable may not add to the total due to missing values.
Proportion of patients endorsing individual domains of patient-centred care

Table 3 shows the number and proportion of radiation oncology patients who agreed that their well-being could have been improved by better care across eight different domains of patient-centred care. It can be seen that each domain was endorsed by between 12% and 22% of patients.

Characteristics associated with endorsement of domains

Multiple logistic regression analysis identified that Australian-born participants had lower odds of endorsing perceiving ‘better management of physical symptoms’ would have greatly improved their well-being (OR=0.4; 95% CI 0.2 to 0.7; p=0.0008). No other characteristics were significantly associated with endorsing better management of physical symptoms.

Better information and communication about my cancer and care: Australian-born patients had lower odds of perceiving that ‘better information and communication about my cancer and care’ would have greatly improved their well-being (OR=0.5; 95% CI 0.5 to 0.9; p=0.0153), as did patients living with a partner (OR=0.5; 95% CI 0.3 to 0.8; p=0.0083). It was also found that patients aged 60–69 years (OR=0.3; 95% CI 0.1 to 0.7) and aged 70 or over (OR=0.3; 95% CI 0.2 to 0.8) had lower odds of endorsing this domain than younger participants (p=0.0042). Patients with a likely presence of depression had three times the odds of endorsing this domain (OR=3.1; 95% CI 1.1 to 9.0; p=0.0396).

Better emotional and/or spiritual support: patients aged 60–69 years (OR=0.3; 95% CI 0.1 to 0.6) and aged 70 or over (OR=0.4; 95% CI 0.2 to 0.8) had lower odds of endorsing this domain compared with younger participants (p=0.0011). Australian-born patients had lower odds of endorsing this domain (OR=0.3; 95% CI 0.2 to 0.5; p<0.0001), while patients with clinically significant levels of depression had higher odds of endorsing (OR=3.5; 95% CI 1.2 to 10.1; p=0.0250).

Better services, information and support for my friends/family: lower odds of endorsing this domain were found in older patients aged 60–69 years (OR=0.2; 95% CI 0.1 to 0.5) and aged 70 or over (OR=0.2; 95% CI 0.1 to 0.4) compared with younger participants (p<0.0001), and also in Australian-born patients (OR=0.4; 95% CI 0.2 to 0.6; p=0.0004).

Better staff approachability and respect for me: Australian-born patients had significantly lower odds of endorsing this domain (OR=0.3; 95% CI 0.1 to 0.5; p=0.0001). Marginally non-significantly lower odds of endorsing this domain were found in older patients aged 60–69 years (OR=0.3; 95% CI 0.1 to 0.9) compared with younger participants (p=0.0683).

Getting better access to the care I need when required: older patients aged 60–69 years (OR=0.2; 95% CI 0.1 to 0.5) and aged 70 or over (OR=0.3; 95% CI 0.1 to 0.8) had lower odds of endorsing this domain compared with younger participants (p=0.0003). Once again, Australian-born patients had lower odds of endorsing this domain (OR=0.3; 95% CI 0.2 to 0.6; p=0.0003). Marginally non-significantly lower odds were also found in socioeconomic group 2 (OR=0.2; 95% CI 0.1 to 0.9) and group 3 (OR=0.3; 95% CI 0.1 to 0.9) compared with the lowest socioeconomic group (p=0.0837).

Better services/support to cope with changes to my relationships: older patients aged 60–69 years (OR=0.1; 95% CI 0.1 to 0.4) and aged 70 or over (OR=0.2; 95% CI 0.1 to 0.4) had lower odds of endorsing this domain compared with younger participants (p=0.0001). Once again, Australian-born patients had lower odds of endorsing this domain (OR=0.3; 95% CI 0.1 to 0.5; p=0.0001). Patients with clinically significant levels of depression had higher odds of endorsing this domain (OR=7.2; 95% CI 2.3 to 22.5; p=0.0007).

Better services/advice to assist me with practical concerns: older patients aged 60–69 years (OR=0.1; 95% CI 0.1 to 0.3) and aged 70 or over (OR=0.3; 95% CI 0.1 to 0.6) had lower odds of endorsing this domain compared with younger participants (p=0.0001). Australian-born patients also had lower odds of endorsing this domain (OR=0.5; 95% CI 0.3 to 0.8; p=0.0070).

Table 3 Proportion who reported that their well-being would have been improved by better care across eight domains (n=344)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Agreed (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and communication about my cancer and care</td>
<td>76 (22, 18–27)</td>
</tr>
<tr>
<td>Emotional and/or spiritual support</td>
<td>75 (22, 18–27)</td>
</tr>
<tr>
<td>Management of my physical symptoms</td>
<td>72 (21, 17–26)</td>
</tr>
<tr>
<td>Services; information and support for my friends/family</td>
<td>72 (21, 17–26)</td>
</tr>
<tr>
<td>Services/advice to assist me with practical concerns</td>
<td>69 (20, 16–25)</td>
</tr>
<tr>
<td>Access to the care I need when required</td>
<td>62 (18, 14–23)</td>
</tr>
<tr>
<td>Services/support to cope with changes to my relationships</td>
<td>56 (16, 13–21)</td>
</tr>
<tr>
<td>Staff approachability and respect for me</td>
<td>42 (12, 8.9–16)</td>
</tr>
</tbody>
</table>

Proportion of patients endorsing multiple domains where better care would have improved their well-being

Figure 1 shows the percentage of respondents endorsing none, one and multiple domains where better care would have improved their well-being. Overall, 31% of respondents (n=107) endorsed multiple domains where they agreed or strongly agreed that their well-being could have been improved by better care.

For 55% of participants, it was perceived that improvement in well-being would not have resulted from better care in any of the examined domains. Fourteen per cent of participants identified only one domain where better care would have greatly improved their well-being.
Table 4 shows the results of analyses examining factors associated with the perception that well-being could have been improved by better care in multiple (2 or more) domains. It can be seen that compared with the younger age group (18–49 years), being aged 60 years or over was associated with significantly lower odds of endorsing multiple domains as requiring improvement. Additionally, relative to patients not born in Australia, those who were Australian-born had significantly lower odds of endorsing multiple domains in which well-being would have been improved by better care. Outpatients living with a partner had significantly lower odds of identifying multiple domains where better care would have greatly improved their well-being. There were significantly higher odds of endorsing multiple domains among outpatients with a likely presence of anxiety.

DISCUSSION
In which domains would better care greatly improve well-being for the most patients?

For each of the eight domains of care assessed, between 12% and 22% of respondents agreed or strongly agreed that their well-being would have greatly improved with better care. One-fifth or more agreed that improvements to the following domains would have improved their care: better information and communication about my cancer and care (22%); better emotional and/or spiritual support (22%); better management of physical symptoms (21%); better services information and support for friends/family (21%) and better services/advice to assist with practical concerns (20%). Overall, these frequencies were lower than identified in comparable domains in recent international studies of experiences of care in patients with cancer in Australia, New Zealand, British Colombia, Canada and Europe.\(^ {11, 13, 18, 35, 36}\) This discrepancy may be a consequence of the differences in measures. Although past measures have assessed experiences of care or unmet need, they have not assessed the impact that patients perceive better care in these patient-centred domains would have on their well-being. Alternatively, the discrepancies between findings may be a result of improved delivery of patient-centred care over time.

Characteristics associated with endorsing each domain of patient-centred care

Country of birth

Australian-born patients had lower odds of endorsing each of the assessed domains of patient-centred care. It may be that Australian-born patients perceive that they are receiving better care than migrants. Alternatively, it may be that Australian-born patients have lower expectations of care and of the degree to which their well-being would be improved by better care.\(^ {37}\) Linguistic and cultural barriers to patient perceptions of high-quality healthcare have been previously identified, highlighting the need for responsiveness to cultural background for optimal healthcare delivery.\(^ {37}\) Although the current research was limited to patients with adequate English to complete the survey, there has been increased research attention on some of these challenges faced by people with cancer from culturally and linguistically diverse backgrounds in Australia.\(^ {38, 39}\)

Age group

Older age was associated with lower odds of endorsing a need for improvement in all domains of patient-centred care, with the exception of management of physical symptoms and staff approachability and respect for the patient. This is consistent with previous studies suggesting that older age is associated with higher overall patient satisfaction ratings\(^ {40}\) and that older patients...
undergoing radiation treatment have lower information needs. It may be that older patients perceive pain management and interpersonal care as a traditional role of the doctor, leading to similar perceptions about the need for improvement in these domains as held by younger age groups.

Patients with HADS classified depression had higher odds of endorsing the following three domains than non-depressed respondents: information and communication about cancer and care; emotional and spiritual support and support with changes to relationships.

<p>| Table 4 Demographic, disease and HADS associations with endorsement of multiple domains as requiring improvement† |
|--------------------------------------------------|--------------------------------------------------|--------------------------------------------------|</p>
<table>
<thead>
<tr>
<th>Hospital endorsed n (%)</th>
<th>LR χ², p value</th>
<th>Unadjusted OR (95% CI)‡</th>
<th>Adjusted OR (95% CI)‡</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital 5.0, p=0.1752</td>
<td>2.9, p=0.4002</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site 1 36 (36%)</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Site 2 22 (23%)</td>
<td>0.5 (0.3 to 1.0)</td>
<td>0.6 (0.3 to 1.2)</td>
<td></td>
</tr>
<tr>
<td>Site 3 23 (32%)</td>
<td>0.8 (0.4 to 1.6)</td>
<td>0.9 (0.4 to 1.8)</td>
<td></td>
</tr>
<tr>
<td>Site 4 26 (34%)</td>
<td>0.9 (0.5 to 1.7)</td>
<td>1.0 (0.5 to 2.0)</td>
<td></td>
</tr>
<tr>
<td>Age category</td>
<td>35.9, p&lt;0.0001</td>
<td>28.9, p&lt;0.0001****</td>
<td></td>
</tr>
<tr>
<td>18–49 years 36 (51%)</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>50–59 years 34 (46%)</td>
<td>0.8 (0.4 to 1.5)</td>
<td>0.7 (0.4 to 1.4)</td>
<td></td>
</tr>
<tr>
<td>60–69 years 20 (18%)</td>
<td>0.2 (0.1 to 0.4)</td>
<td>0.2 (0.1 to 0.4)</td>
<td></td>
</tr>
<tr>
<td>70 years plus 17 (19%)</td>
<td>0.2 (0.1 to 0.4)</td>
<td>0.2 (0.1 to 0.5)</td>
<td></td>
</tr>
<tr>
<td>Sex§</td>
<td>2.5, p=0.1159</td>
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<tr>
<td>Male 48 (27%)</td>
<td>1.0</td>
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<tr>
<td>Female 59 (35%)</td>
<td>1.4 (0.9 to 2.3)</td>
<td></td>
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<tr>
<td>Cancer type§</td>
<td>3.8, p=0.1469</td>
<td></td>
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<tr>
<td>Breast 31 (33%)</td>
<td>1.0</td>
<td></td>
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<tr>
<td>Prostate 16 (22%)</td>
<td>0.6 (0.3 to 1.1)</td>
<td></td>
<td></td>
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<tr>
<td>Other cancer types¶</td>
<td>0.6 (0.3 to 1.1)</td>
<td></td>
<td></td>
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<tr>
<td>Second diagnosis or recurrence</td>
<td>1.0, p=0.3123</td>
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<tr>
<td>No 81 (33%)</td>
<td>1.0</td>
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<td></td>
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<tr>
<td>Yes 26 (27%)</td>
<td>0.8 (0.5 to 1.3)</td>
<td></td>
<td></td>
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<tr>
<td>Born in Australia</td>
<td>8.5, p=0.0037</td>
<td>5.4, p=0.0205*</td>
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<tr>
<td>No 47 (42%)</td>
<td>1.0</td>
<td>1.0</td>
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<tr>
<td>Yes 60 (26%)</td>
<td>0.5 (0.3 to 0.8)</td>
<td>0.5 (0.3 to 0.9)</td>
<td></td>
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<tr>
<td>Socioeconomic status</td>
<td>0.3, p=0.5758</td>
<td></td>
<td></td>
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<tr>
<td>Low 5 (22%)</td>
<td>1.0</td>
<td></td>
<td></td>
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<tr>
<td>Medium 8 (16%)</td>
<td>0.7 (0.2 to 2.4)</td>
<td></td>
<td></td>
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<tr>
<td>High 59 (22%)</td>
<td>1.0 (0.4 to 2.9)</td>
<td></td>
<td></td>
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<tr>
<td>Usual place of residence</td>
<td>0.3, p=0.5758</td>
<td></td>
<td></td>
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<tr>
<td>Major city 87 (32%)</td>
<td>1.0</td>
<td></td>
<td></td>
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<tr>
<td>Regional or rural 19 (28%)</td>
<td>0.8 (0.5 to 1.5)</td>
<td></td>
<td></td>
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<tr>
<td>Living with partner</td>
<td>5.2, p=0.0224</td>
<td>3.9, p=0.0481*</td>
<td></td>
</tr>
<tr>
<td>No 50 (38%)</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Yes 57 (27%)</td>
<td>0.6 (0.4 to 0.9)</td>
<td>0.6 (0.4 to 1.0)</td>
<td></td>
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<tr>
<td>Clinically significant anxiety††</td>
<td>10.4, p=0.0013</td>
<td>4.3, p=0.0383*</td>
<td></td>
</tr>
<tr>
<td>No 82 (28%)</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
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<tr>
<td>Yes 25 (52%)</td>
<td>2.8 (1.5 to 5.2)</td>
<td>2.1 (1.0 to 4.1)</td>
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<tr>
<td>Clinically significant depression§††</td>
<td>5.7, p=0.0167</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No 97 (30%)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes 10 (59%)</td>
<td>3.3 (1.2 to 9.0)</td>
<td></td>
<td></td>
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<tr>
<td>Completed radiation therapy appointments</td>
<td>0.02, p=0.8893</td>
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</table>

Note: Observations within each variable may not add to the total due to missing values.

†p<0.05 ‡p<0.01 ***p<0.001 ****p<0.0001
†p-values for the Hosmer-Lemeshow goodness of fit test were between 0.2 and 0.9 for specific domain models; and was 0.1 for the multiple domain model (Table 4 description, line 755).
‡Reported p-values are from the Likelihood ratio test (Table 4, Column 3 and 4 headers).
§Eliminated during backwards stepwise multiple logistic regression analysis.
¶Including brain, colorectal, head and neck, lung, non-Hodgkin’s lymphoma, and other cancer types.
††Assessed using the Hospital Anxiety and Depression Scale (HADS).
Patient-centred cancer care

A diagnosis of chronic disease with comorbid depression has previously been associated with perceptions of poor doctor–patient communication. This may be because depressive symptoms such as negative affect may make interactions with healthcare providers more strained and less effective than for non-depressed patients. Alternatively, it may be that there are patient recall difficulties arising from depressive symptoms such as poor concentration, leading to negative patient perceptions of information provision and communication.

Socioeconomic status

Higher socioeconomic groups were found to have marginally significantly lower odds of endorsing issues relating to getting access to care when required. Patients from higher SES areas may be more likely to live in wealthier urban areas that are closer to healthcare facilities, and therefore have less difficulties with access. Given Australia’s dispersed population, access to cancer care service delivery can be challenging for patients from lower SES areas, particularly those in rural and regional areas. This is particularly the case for accessing RT treatment, which is only available in metropolitan centres and very few major regional centres.

Multiple domains of patient-centred care: characteristics of particularly vulnerable groups

Overall, 31% of patients indicated that better care in multiple domains of patient-centred care would have greatly improved their well-being. Older patients had lower odds of reporting that improvements in their care needed multiple domains of care. This finding has been frequently reported in patient satisfaction research. It has been suggested that this may reflect differences in the expectations or preferences of care of older people compared with younger people. Consistent with the findings across the individual domains of care, patients born in Australia had lower odds of endorsing multiple domains where better care would have greatly improved their well-being. This is consistent with findings of lower patient satisfaction that have been reported in migrant groups in international settings.

A significant trend towards having lower odds of reporting improvements in their care was seen in those respondents living with a partner. Spranger et al reported that the quality of life in individuals with chronic disease was higher among those with a partner. Family members and carers may play an important role in assisting patients to navigate the healthcare system and may advocate on the patient’s behalf. Patients’ self-management skills may also be complemented by having a support person; however, these findings warrant further exploration in cancer settings.

As expected, an association was found between clinically significant anxiety levels and patients’ perceptions that their well-being could be improved by better care across multiple patient-centred domains. This is consistent with findings suggesting that individuals suffering from elevated levels of anxiety may be more likely to be critical of the healthcare system. Alternatively, anxiety may affect interactions with healthcare providers and the effectiveness of help-seeking behaviours, resulting in the receipt of poorer care across multiple domains. This finding suggests that there is a need to identify these patients in clinical practice and reduce their perceived room for improvement in well-being by alleviating their anxiety and improving their perceptions of care. There have been some partially successful intervention studies conducted in radiotherapy settings and more generally that have aimed to improve patient-centredness of care.

Strengths and limitations

The current study achieved a high consent rate compared with recent research examining cancer outpatient satisfaction with care, and to the best of our knowledge, it is also the first large study to assess patient-centred care in RT outpatients. Heterogeneous cancer sites and stages were included to provide clinics with information about which patient groups may be missing out on elements of patient-centred care. The quality of care measure was developed following extensive pilot testing and with reference to the literature, and the domains have been supported by a recent qualitative study with radiation oncology patients. Therefore, it appears to have face validity as well as internal reliability. However, further examination of its psychometric properties is needed. Demographic information was collected via patient self-report. While the accuracy of this method has been questioned, it has been shown to produce reliable responses for these demographic variables, and is a cost-effective and feasible way of collecting these data.

It should also be noted that owing to extended pilot testing and low survey completion rates, our final sample size was smaller than planned. However, given that the proportion of patients perceiving the need for better care in each domain was lower than expected, we were still able to obtain prevalence estimates with 95% CIs within ±5% of the point estimate, and detect differences of approximately 15% in characteristics between those who did and did not perceive the need for better care in each domain of care with 80% power and 5% significance level.

CONCLUSIONS

Thirty-one per cent of respondents identified that better care across multiple domains would have greatly improved their well-being. ‘Information and education’, ‘emotional and spiritual support’, ‘management of physical symptoms’ and ‘involvement of friends and family’ were the four domains most commonly identified where better care would have increased respondent well-being.
Older patients and patients born in Australia had significantly lower odds of identifying multiple domains of patient-centred care where better care would have improved their well-being. This suggests that younger patients and migrants to Australia appear to be more likely to identify that better care would be of benefit to their well-being. Further investigation of how these factors interact with well-being and the provision of patient-centred care may assist in developing targeted interventions to improve outcomes for these groups.

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**Contributors** LM was involved in the conception of the manuscript, study design, coordination of patient recruitment and management of data collection, statistical analysis and data interpretation. MC was involved in the conception of the manuscript, study design, coordination of patient recruitment and data interpretation. RS-F initiated the manuscript conception, and was involved in the study design, coordination of patient recruitment and data interpretation. CDF was involved in study design and provided statistical support including data interpretation for the manuscript. All authors contributed to manuscript drafting and revisions for important intellectual content, and approved of this final version of the manuscript.

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**Competing interests** None.

**Ethics approval** The study was approved by a University of Newcastle Human Research Ethics Committee and the New South Wales Population and Health Services Research Ethics Committee. Relevant institutional approvals were also obtained for participating hospitals.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** No additional data are available.

**REFERENCES**


Patient-centred cancer care


Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey


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Statement of contribution

I, Laureate Professor Rob Sanson-Fisher, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


14/08/20

Laureate Professor Rob Sanson-Fisher (Co-Author) 

16/08/2013

Ms Lisa Mackenzie (Candidate) 

12/09/2013

Professor John Rostas (Assistant Dean Research & Research Training)
Statement of contribution

I, Dr Mariko Carey, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet British Medical Journal authorship guidelines for the following manuscript:


15/8/2013
Dr Mariko Carey (Co-Author) Date

16/08/2013
Ms Lisa Mackenzie (Candidate) Date

12/09/2013
Professor John Rostas (Assistant Dean Research & Research Training) Date
Statement of contribution

I, Professor Catherine D’Este, attest that Research Higher Degree candidate, Ms Lisa Mackenzie, contributed substantially to manuscript conceptualisation, study design, data collection, data analysis and manuscript preparation to meet *British Medical Journal* authorship guidelines for the following manuscript:


\[15/8/2013\]

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Appendix 6: Additional relevant publications

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Appendix 6.1: Published conference abstract

Permission to copy and communicate this work, “Who should make disclosure decisions? Cancer patients’ preferences for life expectancy disclosure”, has been granted by John Wiley and Sons.
BACKGROUND: In recent years, cancer patients have become increasingly proactive with regard to their disease management. Patients entering hospital today are more informed regarding their illness and therapeutic options, necessitating a shift in health care approaches to accommodate this more knowledgeable population of patients. METHOD: In November, 2009, the Regional Cancer Counseling Center in Tuscany initiated a “hot line” for patients and families with the objective of listening and providing information-oriented support and counseling regarding treatment regimens, disease course, resolution, and associated psychological and organizational issues. The hotline is available for 12H daily and is staffed by psychologists, graduate students and health care professionals skilled in oncological services. In collaboration with other professionals, the hot line is committed to providing clear and competent answers to questions within 24-48H. Access and referral is provided through psycho-oncological contacts in the regional health clinics and hospitals throughout Tuscany. RESULTS: In 16 months of operation, the Service responded to 4000 calls, providing support for over 1500 users. Most are cancer patients (42%) or their family members (43%). Interestingly, a small percentage (3%) of users are service providers within the Tuscan Health Service. Questions related to the clinical course of care constitute 55% of applications; of these 23% relate to logistical and organizational issues and 22% to issues of deep emotional and relational suffering. 49% are requests for information on structures and/or specialists, patient rights, waiting periods, examination and treatment. Only 2% are related to reports of adverse events. CONCLUSIONS: Our organization structure provides two layers of intervention. The first is a counselor who establishes contact with the user and the second is the infrastructure of psychologists and cancer experts that allows us to comprehensively address the user’s needs. Our user data, with its trends towards increasing demand for and usage of the hotline, suggests that the hot line provides an innovative service which is meeting the essential needs of citizens who are living with and coping with cancer and its consequences. An unexpected result was the usage of the hotline by health care providers. ACKNOWLEDGEMENT OF FUNDING: None.

II-2


Lisa Mackenzie, Rob Sanson-Fisher, Mariko Carey, Alix Hall
Priority Research Centre for Health Behaviour,
The University of Newcastle, Newcastle, NSW, Australia

BACKGROUND: Life expectancy information is important to many cancer patients. Consensus guidelines suggest that clinicians should take a patient-centred approach to life expectancy disclosure in order to accommodate variation in patient preferences for this information. This involves asking patients whether they want to discuss life expectancy. This research aimed to:

1. assess cancer patients’ willingness to answer survey questions about life expectancy.
2. assess patient preferences for and experiences of life expectancy discussions.

METHOD: Cancer outpatients (n = 564) aged over 18, English speaking and with various cancer types were recruited from radiation therapy treatment centres in Sydney, Australia between February and December 2010 (consent rate 86.4%). The 10–15 minute touch screen computer survey was completed by 471 patients. As part of the survey, respondents were asked if they were willing to answer questions about their life expectancy. Those who opted to complete the life expectancy questions were asked about their preferences for and experiences of life expectancy discussions.

RESULTS: The life expectancy questions were answered by more than two thirds of respondents. Participants who were male, Australian born, younger and diagnosed with breast or prostate cancer were more likely to answer life expectancy questions. Of those who completed the questions, the majority agreed that they would prefer their cancer doctor to ask them before discussing life expectancy. Of the respondents who had discussed their life expectancy, only a small proportion reported that they had experienced an approach to disclosure that was aligned with their preferences. The interpretation of these findings in relation to consensus guidelines will be discussed.

CONCLUSIONS: The majority of respondents indicated a willingness to answer questions about life expectancy. Most of those who answered the questions indicated a preference for a patient-centred approach to disclosure, however patients reported that the initiation of life expectancy discussions was not always in line with this preference. The predictors of opting to answer the questions (including being male, Australian born, younger and diagnosed with breast or prostate cancer diagnosis) should be taken into account when considering the acceptability of life expectancy questions. RESEARCH IMPLICATIONS:
It appears that answering life expectancy questions is acceptable to most cancer patients. However, further research into how cultural background, age, gender and disease type influences acceptability is required. There is a critical need to develop research evidence to guide life expectancy disclosure. Research in this area needs to strike a balance between obtaining important information on patient preferences whilst avoiding harming patients who do not want to be confronted by these types of questions. CLINICAL IMPLICATIONS: Our findings suggest that current practice in Australia does not reflect the available consensus guideline recommendations of a patient-centred approach to prognosis disclosure. Patient preferences are, however, in line with these recommendations - most patients want to be asked if they want to discuss their life expectancy. There is a need to provide feedback to and training for clinicians on how to initiate conversations about life expectancy and to elicit patient preferences for this information. ACKNOWLEDGEMENT OF FUNDING: Lisa Mackenzie’s PhD candidature is supported by a 2009 Professor Jill Cockburn Scholarship.

II-3

What are the Supportive Care Needs of Patients and Family Caregivers Consulting a University-Affiliated Otolaryngology—Head and Neck Surgery Clinic

Melissa Henry1,2, Laura Anne Habib1, Matthew Morrison1, Ji Wei Yang1, Joanna Li Xuejiao1, Shiru Liu1, Michael Hier1,2, Richard Payne1,2, Karen Kost1,2, Anthony Zeitouni1,3, Alex Mlynarek1,2, Christina MacDonald1,2, Martin Black1,2

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BACKGROUND: Up to 50% of head and neck cancer patients (H&N-CP) suffer from clinical anxiety and/or depression, at a higher rate than in the general cancer population and associated with a higher risk of suicide. Yet, no study systematically attempts to understand supportive care needs from the H&N-CP’s perspective. This study aims to identify 1) met and unmet supportive care needs of H&N-CP; and 2) variability in needs according to demographics, disease variables, level of distress and QoL. METHOD: Participants were recruited from Otolaryngology-H&N Surgery clinics of two McGill University teaching hospitals. Self-administered questionnaires included socio-demographic and medical questions, as well as the Supportive Care Needs Survey-Short Form(SCNS-SF34), Hospital Anxiety and Depression Scale(HADS), and FACT-G and FACT-H&N(QoL measures). RESULTS: H&N-CP(n = 134) were mostly men(67.6%), x = 61yrs(sd 12.4), married/common-law(66.9%) and initially diagnosed <5yrs(85.7%), 24.8% and 26.9% of patients and caregivers, respectively, had a high distress level(HADS > 16) and 68.2% and 81.1% experienced some area of unmet need. For patients, areas of highest unmet needs mostly involved psychological and existential needs(8 of top ten needs). Patients’ and caregivers’ needs were significantly positively correlated (r = 0.61, p < 0.01). A multiple linear regression indicated a higher level of unmet needs when patients were divorced/separated [β = -0.21, p = 0.003], had worse social/family QoLFACT-G subscale]β = -0.45, p = 0.001], and higher anxiety(HADS subscale][β = 0.34, p = 0.001]. Needs did not vary according to disease variables (ie, stage, trajectory phase,treatment,time since diagnosis). CONCLUSIONS: This study is a first attempt at shedding light on the unmet supportive care needs of H&N-CP. identifying psychological and existential needs as priorities for action. RESEARCH IMPLICATIONS: Existential needs have been understudied in H&N-CP and merit further attention. Patients are likely to benefit from Interventions targeting the important domains revealed through this study. Such interventions could subsequently be tested in a RCT. CLINICAL IMPLICATIONS: Results of this study support the importance of psychological distress as the 6th vital sign in H&N-CP. This study highlights that H&N-CP have important unmet psychological/existential needs. Psychosocial interventions, targeting these specific areas, may enhance QoL and prevent distress in this vulnerable oncologic population. Other targets may be those patients with high levels of anxiety and low level of social/family QoL, as these are likely to present higher levels of needs. ACKNOWLEDGEMENT OF FUNDING: None.

JJ-1

“Good Things Come in Three’s?” Patient, Family, and Health Professional Experiences of Triadic Communication and Decision-Making in Cancer Consultations

Rebekah Powell1, Phyllis Butow1, Stella Bu1, Cathy Charles2, Amiram Gafni3, Wendy Lam1, Heather Shepherd1, Kirsten McCaffery4, Jesse Jansen3, Martin Tattersall1, Ilona Juraskova1

1Centre for Medical Psychology and Evidence Based Decision Making, The University of Sydney, NSW, Australia, 2Centre for Health Economics and Policy Analysis, McMaster University, Hamilton, ON, Canada, 3Department of Community Medicine, School of Public Health,
Appendix 6.2: Published poster listings

Permission to copy and communicate these works, “Anxiety and depression during radiotherapy treatment: A comparison of touchscreen computer administration of the Hospital Anxiety and Depression Scale and single-item self-report measures” and “Japanese cancer patients’ preferences for life expectancy discussions” has been granted by John Wiley and Sons.
IPOS Posters Listings

**General Psycho-Oncology**

Tatsuo Akechi  
Good death among elderly cancer patients in Japan based on perspectives of the general population.  
*abs#401*

Chioma Asuzu  
Smoking behaviour of students in the University of Ibadan, Nigeria.  
*abs#402*

Michele Aubin  
Distress in patients and their natural caregivers early after the diagnosis of inoperable lung cancer.  
*abs#403*

Indrani BasuMallik  
Psychosexual effects of gynaecological cancer survivors in India.  
*abs#404*

Margaret Bennett  
Prostate cancer – men aren’t the only ones.  
*abs#405*

Cristiane Bergerot  
Integration of the health team to address the patients’ emotional aspects: caring for the whole patient.  
*abs#406*

Charlotte Bradley-Peni  
Reports from patients with advanced cancer and their caregivers of their health related quality of life (HRQoL).  
*abs#407*

Anne Brédart  
Posttraumatic growth in adult cancer survivors: a critical review of empirical research using the organismic valuing theory of growth.  
*abs#408*

Joanne Brooker  
Mental disorders in people diagnosed with cancer: findings from the 2007 Australian National Survey of Mental Health and Wellbeing.  
*abs#409*

Maria Brovall  
Stressful events and coping strategies among postmenopausal women during active treatment for primary or recurrent breast cancer.  
*abs#410*

Richard Brown  
Employee to employer communication skills: balancing cancer treatment and employment.  
*abs#411*

Richard Brown  
African American cancer patients’ perceptions of participation in a phase I, II, or III clinical trial: what do refusers say?  
*abs#412*

Timothy Chan  
*abs#413*

Irene Cheung  
*abs#414*

Katherine Chisholm  
Predictors of engagement in an online psychological support program for men treated for prostate cancer.  
*abs#415*
Cristina Civilotti
Using the distress thermometer and the hospital anxiety and depression scale in Italian women newly diagnosed with breast cancer.  

Samantha Clutton
The implementation of a mindfulness group programme throughout the state of Queensland.  

Denise Corboy
Intentions to use telephone and face-to-face support services: attitudes of Australian men following prostatectomy.  

Tammy Corica
Patient preferences for adjuvant radiotherapy in early breast cancer – an Australian sub-study of the International TARGIT trial.  

Rosario Costas-Muniz
Informational needs and deficits of Latinas diagnosed with breast cancer.  

Pia Dellson
Use of graphic design to facilitate reading and understanding of written patient information in clinical cancer trials.  

Jayita Deodhar
Demographic factors, referral patterns and clinical correlates in Adjustment Disorder in cancer patient referrals to an in-house liaison psychiatry service in a tertiary care oncology hospital in India.  

Jayita Deodhar
Evaluation of a training module on client centered counseling in cancer conducted for volunteers working in oncology in a tertiary care cancer hospital in India.  

Barb Donnan
Addressing the educational and psycho-social needs of children and adolescents diagnosed and treated for cancer in Australia.  

Sue Duke
Does it do what it says on the tin? An evaluation of using a licensed communication skills training product within a regional education strategy to increase capability and capacity in end of life care.  

Jaklin Eliott
‘It’s a very difficult balance’: a qualitative study of cancer specialists’ perceptions of discussing Complementary and Alternative Medicine with their patients.  

Chun-Kai Fang
Association among depression, demoralization, and posttraumatic growth in cancer patient: preliminary study.  

Ingeborg Farver

Léonor Fasse
‘What should be taught to future clinicians and health-care professionals regarding grief reactions in the cancer field?’.  

Léonor Fasse
Current definitions and measures of quality of life in pediatric palliative care: a systematic review.
Léonor Fasse
A systematic review comparing quality of life definitions and measurement strategies between adult palliative care and pediatric palliative care. \textit{abs\#432}

Roberta Fenili
Daily bad news in stage IV cancer inpatients. \textit{abs\#433}

Debbie Fenlon
Lessons learnt from setting up a multi-centre cohort study in the UK: a cohort study to explore recovery of health and well-being following primary treatment of colo-rectal cancer (CREW (ColoRectal Wellbeing) cohort). \textit{abs\#434}

Brooke Filsinger
Why don’t people get screened for cancer? Preliminary results from an online survey reaching under and never screened populations. \textit{abs\#435}

Margaret Fitch
Implementing a national strategy for achieving person-centered care: the need for multiple strategies. \textit{abs\#436}

Cécile Flahault
Effects of family therapy on the communication of patient suffering from cancer and its family. \textit{abs\#437}

Maiko Fujimori
An exploratory study on factors associated with patient preferences for communication. \textit{abs\#438}

Annie Gayed
\textit{Hope & Hurdles}: an information resource for women with secondary breast cancer. \textit{abs\#439}

Afaf Girgis
Applying an evidence-based approach to development and evaluation of resources for families facing advanced cancer: lessons learned from the ‘Consumer Toolkit’. \textit{abs\#440}

Ainslie Hannan
‘I know you think there is this system: but this is what actually happened to me?’ Translating cancer research into a responsive supportive care system of services, programs and policies. \textit{abs\#441}

Josette Hoekstra-Weebers
Cancer patients’ opinions of psychosocial screening. \textit{abs\#442}

Lesley Howells
‘Where now?’ – Pilot study of a course for people living beyond cancer. \textit{abs\#443}

Sheng Hui Hsu
Are there differences between the written and the oral means of screening psychosocial distress with the Distress Thermometer in cancer patients? \textit{abs\#444}

Wen-Yau Hsu
The bidirectional relationships of coping strategies and distress: a study among Taiwanese newly-diagnosed breast cancer patients. \textit{abs\#445}

Nick Hulbert-Williams
Developing a nationally collaborative framework for psychosocial oncology research: a review of the UK NCRI psychosocial oncology clinical studies group. \textit{abs\#446}

Chiaki Ihara
Spirituality and meaning in life of the Japanese female breast cancer patients. \textit{abs\#447}

Monika Janda
Depression predicts lower use of services in gynaecological cancer survivors. \textit{abs\#448}
SunJoo Jang
A randomized, controlled trial of meditation for women with breast cancer.  *abs#449*

Nadine Kasparian
‘Living beneath the sword of Damocles’: perceptions of risk and fears of cancer recurrence amongst Australian melanoma survivors at high or moderate risk of developing new primary disease.  *abs#450*

Colleen Kendrick
‘The critical ingredients of success’: evaluation findings of a supervised exercise programme for men who have had a diagnosis of cancer.  *abs#451*

David Kinyanjui
Psychosocial impact of a cancer diagnosis on patients and families in Subsaharan Africa.  *abs#452*

Nadja Klafke
Men with cancer using Complementary and Alternative Medicine (CAM): variations in significant others’ involvement.  *abs#453*

Tamara Klikovac
Attitude to psycho-oncology and palliative care in Serbia today (descriptive presentation).  *abs#454*

Tamara Klikovac
Psychological support for parents, teens and adolescents during the treatment when a child or teen dies at the Oncological department.  *abs#455*

Marie Koitsalu
Population survey on Swedish women’s attitudes towards tailored mammography screening based on individual risk for breast cancer.  *abs#456*

Kirushna Kumar Kosanam Subramanian
Are caregivers of cancer patients depressed? – A single centre experience from South India.  *abs#457*

Kirushna Kumar Kosanam Subramanian
Factors influencing the treatment choices in early stage newly diagnosed carcinoma cervix patients – a single centre experience from South India.  *abs#458*

Galina Kuznecova
Targets for psychosocial treatment: family and work after breast cancer.  *abs#459*

Sylvie Lambert
Couples coping with cancer: a qualitative study of the views of health care providers.  *abs#460*

Heather Lane
Exploration of the experiences and decision making of older people with cancer.  *abs#461*

Sheleigh Lawler
Transition to follow-up care after breast cancer treatment in rural Australia: women’s experiences of service provision.  *abs#462*

Isabel Leal
A cognitive behavioural intervention on biopsychosocial factors in patients with cancer fatigue – a comparative, correlational study.  *abs#463*

Isabel Leal
Quality of life, posttraumatic stress and posttraumatic growth in breast cancer survivors.  *abs#464*

Byung Ook Lee
The epidemiology of psychiatric disorders among women with breast cancer in South Korea: analysis of the national registry data.  *abs#465*
Tammy Yuk Chun Leung
Pre & post effects of the community support services on the QOL of cancer patients in Hong Kong.  abs#466

Janelle Levesque
Benefit finding in parental cancer: prevalence, types and predictors.  abs#467

Jun-E Liu
Posttraumatic growth levels and their influencing factors among Chinese breast cancer patients.  abs#468

Deborah Lo-Fo-Wong
Complementary and alternative medicine use of women with breast cancer: self-help CAM attracts other women than guided CAM therapies.  abs#469

Clementine Lopez
Arthralgia with aromatase inhibitors: association with quality of life, emotional state and fear of recurrence.  abs#470

Lisa Mackenzie
Anxiety and depression during radiotherapy treatment: a comparison of touchscreen computer administration of the Hospital Anxiety and Depression Scale and single-item self-report measures.  abs#471

Karen Matthews
Establishing a multidisciplinary service, the Hunter & Northern NSW Youth Cancer Service, Australia.  abs#472

Lina Mayorga
Adolescent and Young Adult (AYA) task force: identifying and evaluating educational and psychosocial needs of AYA's.  abs#473

Fiona McDonald
The importance of health literacy to adolescent and young adult cancer patients.  abs#474

Rebecca Mercieca-Bebber
Ovarian cancer patients’ expectations of palliative chemotherapy: the fine line between hope and misunderstanding.  abs#475

Bronwyn Morris
The lived experience of breast cancer survivors participating in challenge-based peer support programs: the transformative effect of riding motorcycles.  abs#476

Fritz Muthny
Need for psychosocial care – expressed by patients in primary treatment.  abs#477

Tomohiro Nakaguchi
Oncology nurses’ recognition of supportive care needs and symptoms of their cancer patients undergoing chemotherapy.  abs#478

Louise Nelson
Prevalence of ‘Problem List’ symptoms among oncology outpatients and relationship with distress.  abs#479

Kittikorn Nilmanat
Psychosocial concerns and coping strategies of patients with advanced stage hepatobiliary cancer.  abs#480

Emma O'Brien
The effect of a specific music therapy songwriting protocol on adult cancer patients mood – a mixed method, multi-site, randomized, wait-list controlled trial.  abs#481

Erin O'Carroll Bantum
Identifying emotion in text generated from online interventions for people who have survived cancer.  abs#482
Masatomo Otsuka
Early palliative care improves the prognosis of cancer patients.  abs#483

Miwa Ozawa
Posttraumatic stress symptoms as an important reaction in children who donate their stem cell to their siblings with cancer.  abs#484

Shuichi Ozono
Posttraumatic stress symptoms among parents of childhood cancer in transition from inpatient to outpatient settings.  abs#485

Jose Pais-Ribeiro
Comparison of quality of life between cancer survivors and people with chronic stable diseases.  abs#486

Louis Penner
From a distance: the influence of dispositions and self-distanced analyses on affect among parents of pediatric cancer patients.  abs#487

Judith Prins
What happens online? Pilot evaluation of how breast cancer survivors use the non-guided Internet-based self-management intervention BREATH.  abs#488

Astrid Przedziecki
My changed body: breast cancer, body image, distress and self-compassion.  abs#489

Lisa Reynolds
Avoidance of disgust’s elicitors in colorectal contexts: mindfulness predicts avoidance when avoidance makes sense.  abs#490

Afsaneh Roshanai
Factors influencing primary care physicians’ decision to order prostate-specific antigen (PSA) test for healthy men.  abs#491

Ursula Sansom-Daly
The effects of rumination on illness-related future thinking in young people: implications for promoting resilience after cancer.  abs#492

Andrea Schumacher
Resilience in cancer survivors after allogeneic hematopoietic stem cell transplantation.  abs#493

Lyndel Shand
Correlates of post-traumatic stress disorder (PTSD) and post-traumatic growth (PTG) in oncology populations: a systematic review and meta-analysis.  abs#494

Kerry Sherman
Supporting Men, Supporting Women: development of a web-based information and support resource for support partners of women undergoing genetic testing for breast cancer risk.  abs#495

Ken Shimizu
Clinical bio-psycho-social risk factors for depression in lung cancer patients: a comprehensive analysis using data from the Lung Cancer Database Project.  abs#496

Shiow-Ching Shun
Comparison between patients with hepatitis C and hepatocellular carcinoma in quality of life and its related factors during receiving treatment.  abs#497

Amanda Spillare
‘There is no information for us’ – the development of the first Victorian gay men’s prostate cancer support group.  abs#498
J Spisz  
The use of a Personality/Stress Questionnaire in the prediction of cancer or CHD in healthy probands.  

Koji Sugano  
Experience of death conference at general hospital setting in Japan.  

Miyako Takahashi  
Sexual function among young breast cancer survivors in Japan correlates with sexual communication with their partners.  

Rie Tamagawa  
Emotional expression in spoken narratives and diurnal cortisol rhythms among women with metastatic breast cancer participating in supportive expressive group therapy.  

Rie Tamagawa  
Associations between depressive mood, health behaviour, and diurnal cortisol slopes among women with breast cancer.  

Melissa Huiliang Tang  
A systematic review of the recent quality of life studies in adult extremity sarcoma survivors: need for further research to assess role of psychological distress in influencing overall outcomes.  

Belinda Thewes  
Fear of cancer recurrence in young breast cancer survivors: the role of meta-cognitive style and disease-related factors.  

Thordis Thorsteinsdottir  
Intrusive thoughts after prostate cancer diagnosis and surgery.  

Thordis Thorsteinsdottir  
Thinking about one’s own death when diagnosed with prostate cancer.  

Luzia Travado  
Cancer patients’ rehabilitation in Europe: results from the Eurochip-3 project.  

Luzia Travado  
Breast cancer meanings: a cognitive-developmental study.  

Luzia Travado  
Sense-of-coherence in breast cancer: is it protective of psychological morbidity?  

Miyako Tsuchiya  
Expected friends reactions to cancer disclosure: an exploratory vignettes study among Japanese cancer survivors.  

Ruchan Uslu  
Building a psycho-oncology unit at a cancer center. Is this really one of the ways to break the stigma related to psychiatric care among cancer patients?  

Mélanie Vachon  
Research informing practice: how can we translate hope in the palliative care practice?  

Ging-Long Wang  
Follow-up contacts with the psychosocial care team after screening for distress in newly diagnosed cancer patients.  

Wei Ting Wang  
Testing reciprocal relationships between coping and post-traumatic growth among breast cancer patients: a cross-lagged structural equation study of approach, emotional, and disengage coping.
Cordula Wetzel
Psychosocial factors in medical decision making of the multidisciplinary team for cancer treatment – an observational study.  abs#516

Hayley Whitford
Spiritual wellbeing in caregivers of geriatric cancer survivors: the association of peace, meaning, and faith to psychological morbidity and resilience.  abs#517

Helen Wilson
The impact of cancer on development in adolescent and young adults: perspectives from patients and health professionals.  abs#518

Kam Fung Wong
Death anxiety reduction after attending the psychological group tackling spiritual concerns.  abs#519

Sima Zadeh
My Choice, My Voice: end of life planning with adolescents and young adults.  abs#520

Nor Zuraida Zainal
Depression and anxiety in breast cancer patients undergoing chemotherapy.  abs#521

**Ongoing Trials in Progress (Oral/Poster Presentations)**

Ben Britton
EAT: a stepped wedge cluster randomised trial to improve nutrition in head and neck cancer patients undergoing radiotherapy.  abs#522

Emma Lewis
A feasibility study of relaxation therapy plus autohypnotherapy training (HYPREL) for patients with thoracic cancer undergoing radiotherapy.  abs#523

Sue McConaghey
ACT in ACTion: Acceptance and Commitment Therapy (ACT) presented in a group format to cancer patients.  abs#524

Judith Prins
Group medical consultations and iPads for breast cancer survivors: from pilot study to RCT.  abs#525

Judith Prins
Nurse Intervention Project: a randomized controlled trial to assess the (cost) effectiveness of the use of the Distress Thermometer in breast cancer patients.  abs#526

Belinda Rahman
Evaluation of the efficacy of two models of delivering information about treatment-focused genetic testing among young women newly diagnosed with breast cancer.  abs#527

Katherine White
A randomised controlled trial of a theory-based school intervention to improve sun-protective behaviour among adolescents.  abs#528
IPOS Posters – The Best of the Best

Margaret Fitch
Implementing survivorship care plans in a Canadian environment; understanding the barriers. abs#529

Jeanelle Folbrecht
Psychosocial services utilized by older adolescents and young adults at a comprehensive cancer center. abs#530

Louise Heiniger
Psychological correlates of not undergoing genetic testing: a systematic review. abs#531

Maria Ho
A qualitative focus group study to identify the needs of colorectal cancer survivors. abs#532

Kristy Hodgson
The effect of chemotherapy on cognition in patients with colorectal cancer. abs#533

E Lobb
Features of gender and grief reported in the experiences of family care-givers six months after a family member’s death from ovarian cancer. abs#534

Lisa Mackenzie
Perceptions of patient-centred cancer care during radiotherapy treatment: a cross sectional survey. abs#535

Sundresan Naicker
Which test is best? – A RCT to evaluate family history as a triage tool in screening for colorectal cancer. abs#536

Patricia Rolls
A prospective study of the role of client variables in distress and therapy outcome within a community cancer counselling service. abs#538

Soo hyun Shin
Screening childhood cancer survivors with the Pediatric Quality of Life: clinical utility relative to the Youth Self Report. abs#539

Sue Sinclair
Clinical practice guidelines for the psychosocial care of adults with cancer: updating and priorities for Australian health professionals. abs#540

Adrian Wan
Does social support mean differently for cancer patients and their family caregivers? A cross-sectional study in a Chinese community. abs#541

Ging-Long Wang
The prevalence and risk factors of psychosocial distress in newly diagnosed cancer patients. abs#542

Soo hyun Shin
Investigating the usefulness of Pediatric Quality of Life Inventory 4.0 as a screening tool for childhood cancer survivors’ psychological difficulties: clinical utility relative to the Childhood Behavior Checklist. abs#543

IPOS Posters – Trials in Progress

Cristiane Bergerot
The data obtained in the first assessment of distress level can indicate future data: evidence into practice. abs#544

Josephine Clayton
Stop Pain Project: a collaborative, interdisciplinary project to improve the person-centredness of assessment and management of cancer pain. abs#545
Debbie Fenlon
Characteristics of cohort and baseline findings: a cohort study to explore recovery of health and well-being following primary treatment of colo-rectal cancer (CREW ( ColoRectal Wellbeing) cohort).  
abs#546

Deborah Lo-Fo-Wong
Quality of care for breast cancer patients: distress, health care needs and use.  
abs#547

Toni Musiello
Routine screening and management of distress in people with cancer in WA: a pilot study of people with haematological malignancies treated in an outpatient setting.  
abs#548

Masakazu Ogura
Agreement between cancer patients and their radiation oncologist regarding diagnosis and prognosis disclosure experiences in Japan.  
abs#549

Clinical Issues, Case Reports and Service Delivery

Elizabeth Akin-Odanye
Impact of the diagnosis of a life threatening illness on purpose in life: implication for practice.  
abs#550

Kanako Amano
The effectiveness of group therapy for the bereaved who have lost their patient to cancer in Japan.  
abs#551

Eugenia Ananyeva
Personal meaning as adaptation resource and specific conditions of survive (Breast Cancer and Gynecology Cancer). 
abs#552

Marina Aralova
Research on primary school pupils’ cognition abilities with oncological diseases.  
abs#553

Hiromi Asada
abs#554

Arza Ashkenazi
Body and soul treatment: music therapy and guided imagery in oncology ward.  
abs#555

Chioma Asuzu
Knowledge, attitude and screening behaviour of secondary school male teachers in Ibadan North Local Government area towards cancer of the prostate.  
abs#556

Joseph Barbuto
Patients with schizophrenia and cancer.  
abs#557

Joseph Barbuto
Cancer as a life-defining event.  
abs#558

Gissell Barreto
Program design for stress management in a group of administrative employees at an Oncology Unit. Caracas–Venezuela.  
abs#559

Gissell Barreto
Relation among resilience, emotional unrest and life quality in patients with cancer attending the Department of Oncology.  
abs#5560

Cristiane Bergerot
Screening for distress and quality of life: the relationship between them and the severity of the disease.  
abs#561
Cristiane Bergerot
Psychosocial factors influence the adaptation of cancer diagnosis/treatment: association between distress and coping styles.  abs#562

Megan Best
Suffering in cancer – conceptualization, assessment and interventions. A systematic literature review.  abs#563

Rachel Brebach
Investigating the engagement of cancer patients and survivors into psychological treatment.  abs#564

Francesco Buda
Psycho-emotional experience and the critical factors in 80 elderly patients undergoing terminal cancer stage.  abs#565

Tracey Bullen
Reducing symptoms with spa therapy – a pilot trial to improve quality of life in palliative care patients [The RESPAT Project].  abs#566

Mahati Chittem
The experience of cancer among informed and non-informed Indian cancer patients: a qualitative study.  abs#567

Ching-Hui Chung
Grief counseling experiences of bereaved children in a memorial service.  abs#568

Cristina Civiliotti
The theme of death in the transcripts of adult attachment interviews in cancer patients: a pilot study.  abs#569

Miri Cohen
Relationships between stressors, depression and salivary pH in older persons who care for spouses with cancer.  abs#570

Rosario Costas-Muniz
Acculturation and unmet practical, supportive and informational needs of Latino cancer patients.  abs#571

Sue De Bono
Self-reported coping strategies and predictors of distress for hospitalised cancer patients.  abs#572

Csaba Degi
Benefits of mindfulness based group therapy on cancer distress and quality of life in hospitalized women with breast cancer in Romania.  abs#573

Mbathio Dieng
Psychological care for people at high risk of melanoma: development and pilot testing of a psycho-educational intervention.  abs#574

Sibel Dogan
‘Effect of relaxation exercise on fatigue, depression and level of quality of life in diagnosed with breast and colorectal cancer within patients under adjuvant chemotherapy’.  abs#575

Jo Anne Dumalaon-Canaria
Psychological outcomes of cancer support group participation among women with breast cancer in the Philippines.  abs#576

Anncommy Ekortarh
The staggering increase of cancer and AIDS patients seen at advanced stage in Yaounde General Hospital: the only way out is a palliative care structure.  abs#577
Babatunde Fadipe  
Psychosocial correlates and depressive symptomatology among attendees of an oncology clinic in West Africa.  
*abs*#578

Omolara Fagbenle  
Effects of palliative care on terminally ill breast cancer patients.  
*abs*#579

Debbie Fenlon  
RESTORE: development and trial protocol of an online intervention to enhance self efficacy to self manage cancer related fatigue following primary treatment.  
*abs*#580

Deborah Fenlon  
Cancer survivors’ self-efficacy to self-manage problems arising from primary cancer and its treatment: results of an online survey.  
*abs*#581

Lise Fillion  
Supporting oncology nurses: introduction to a new program based on meaning and mindfulness.  
*abs*#582

Brooke Filsinger  
Humour and FOBT: taking the fear out of cancer screening for the under and never screened.  
*abs*#583

Margaret Fitch  
Development of a sexual health clinic for gynecologic cancer survivors.  
*abs*#584

Margaret Fitch  
Measuring psychosocial distress in community-based volunteer agencies.  
*abs*#585

Margaret Fitch  
Cancer patient navigation: implementing programmatic approaches.  
*abs*#586

Jane Fletcher  
Cancer rehabilitation in the private sector: establishing a cancer rehabilitation program for women with early stage breast cancer.  
*abs*#587

Liz Forbat  
Family history of breast cancer: clinical implications for relational health promotion derived from a systematic review.  
*abs*#588

Liz Forbat  
Health-promoting communities for families affected by cancer: a qualitative study.  
*abs*#589

Jennifer Fox  
Transition to palliative care for people living with metastatic melanoma: preliminary findings from a grounded theory study.  
*abs*#590

John Friedsam  
What is the nature and the needs of prostate cancer support groups in Australia?  
*abs*#591

Bonnie Furzer  
‘Brighter in thinking, lighter in body and stronger in mind’ Exploring the experiences of patients using complementary therapies.  
*abs*#592

Patrik Göransson  
The development and integration of cancer survivorship strategies at Halmstad Hospital, Sweden, through interaction and participation – a pilot project.  
*abs*#593

Andrea Gregory  
The Specialist Mental health Initiative in Palliative Care (SMIP) Project – development of an integrated psychological service within an established palliative care service.  
*abs*#594
Itzhak Gur
The effect of a unique center for cancer survivors on their subjective wellbeing – the ‘EZER ME-ZION’ experience. abs#595

Thomas Hack
Citation analysis of Canadian psychosocial oncology researchers. abs#596

Jovita Hernández Arista
Development of an interactive multimedia product to facilitate the exchange of emotional state in children with acute lymphoblastic leukemia. abs#597

Caroline Hoffman
Evaluating programmes from The Haven’s breast cancer support centres: results and challenges. abs#598

Nick Hulbert-Williams
Unmet psychosocial needs in haematological cancer: a systematic review of the literature. abs#599

Nick Hulbert-Williams
Living life after cancer treatment: a support group evaluation study. abs#600

Mayumi Ishida
Psychological distress of the bereaved seeking medical counseling at cancer center. abs#601

Sunita Jadhav
Parental trauma: caring 3 children with advanced cancer. abs#602

Yoshiko Katayama
The cancer journey: patients’ personal experiences with an ongoing multidisciplinary approach. abs#603

Seon-Young Kim
Predictors of depression in Korean breast cancer patients: a one year longitudinal study. abs#604

Anita Kinney
Finding a needle in a haystack: population-based approaches to recruiting relatives of CRC patients into a behavioral intervention trial. abs#605

A Kizior
The prediction of cancer or coronary heart disease morbidity by means of the personality/stress questionnaire. abs#606

Kirushna Kumar Kosanam Subramanian
Issues in end of life care and persons involved in decision making – single institutional experience from South India. abs#607

Veronika Koutná
Indication for psychooncology care among volunteer programme participants. abs#608

Atsuko Koyama
The effects of narrative therapy on family members of cancer patients at a specific psycho-oncology outpatient service. abs#609

Lisbeth Lane
Self compassion in the face of uncertainty: the potential contribution of a Buddhist concept to the psychosocial support of cancer patients. abs#610

Isabel Leal
Well-being, stress, anxiety and depression among middle-aged women who are cancer survivors and women with no cancer history. abs#612
Pei-Hsuan Lee
Change of fatigue and physical fitness in hospitalized leukemia patients: a preliminary study.  abs#613

Concha Leon
Would psychological assistance be helpful to me? Prevalence and profile of patients who consider psychological assistance as a resource.  abs#614

Clementine Lopez
An experience of structured support group for the siblings of children with cancer.  abs#615

Cherie Lowe
Co-ordination of psycho-oncology care within the Queensland children’s cancer centre.  abs#616

Lisa Mackenzie
Japanese cancer patients’ preferences for life expectancy discussions.  abs#617

Reiko Makabe
Evidence-based practice of oral care for head and neck cancer patients in Japan: a literature review.  abs#618

Hiromichi Matsuoka
Patient’s prediction of their recovery affects their pain throughout treatment.  abs#619

Sue McConaghey
An innovative approach to the management of cancer-related fatigue.  abs#620

Laura McLaughlan
Facilitating disclosure of complementary therapy use via effective communication.  abs#611

Jessica Medd
street-view.com/: Referral patterns and patient evaluation of clinical psychology services in a urology department.  abs#621

Anja Mehnert
Occurrence and predictors of search for personal meaning and reattribution in patients with lung, breast or ovarian cancer.  abs#622

Gholamhossein Mobaraky
Self esteem in hemophilic, thallassemic and acute cancer patients in Esfahan.  abs#623

Inbar Moshe
Telephone support for cancer patients during treatment: chemotherapy and radiation.  abs#624

Seyed Mahdi Mousavi
Integrating spirituality into a group psychotherapy program base of Iranian-Islamic culture in increasing the general health and quality of life in women with breast cancer.  abs#625

Michael Murphy
Confusion – for patients and clinicians. Potential differences in the management of Delirium in the psycho-oncology setting according to specialty. A case discussion and review of palliative medicine and psychi.  abs#626

Lisa Nielsen
Couple distress following prostate cancer diagnosis.  abs#628

Kittikorn Nilmanat
Voice of suffering among patients with terminal cancer: case studies from Thailand.  abs#629

David Ogez
Effects of psycho-oncological systematic consultation on the distress and adaptation of patients with breast cancer.  abs#630
Ian Olver
Perspectives on Complementary and Alternative Medicines (CAM).  _abs#631_

Luisina Onganía
Somatic vulnerability and depression in oncological patients.  _abs#632_

Angelica Osorio
Self-care manual for women with breast cancer _Towards a Culture of Caring for Themselves_ (Yolanda Panesso Arango).  _abs#633_

Errol Philip
Long-term cancer survivorship: the impact of recurrent disease on psychosocial outcomes.  _abs#634_

Errol Philip
Cancer recurrence and long-term survivorship: symptom burden and desire for support referral.  _abs#635_

Janine Porter-Steele
Sex – let’s talk.  _abs#636_

Shutiwan Purinthrapibal
The characteristics of personal social networks of breast cancer patients in southern Thailand: a qualitative case study.  _abs#637_

Vijayabhaskar Ramakrishnan
Quality of life in patients treated with advanced laryngeal and hypopharyngeal cancers – a single institution experience from southern India.  _abs#638_

Vijayabhaskar Ramakrishnan
Factors affecting treatment options in patients with advanced cancer of oral cavity – a single institution prospective study from Southern India.  _abs#639_

Lauren Spark
Physical activity and dietary interventions in breast cancer survivors: a systematic review of the maintenance of behaviour change outcomes.  _abs#640_

Natalie Stefanic
Investigating resilience in breast cancer: a mixed-methods approach.  _abs#641_

Gunnar Steineck
Worrying about the children after breast cancer: the association between age of the youngest child and mom’s need to talk.  _abs#642_

Anna Stiller
Group peer support in a research setting: training and challenges.  _abs#643_

Norman Straker
Facing the fear of death: 35 years as a psycho oncologist, a psychoanalyst’s perspective.  _abs#644_

Eiji Suzuki
Acceptability of touch screen computer psychosocial survey to Japanese radiation therapy patients.  _abs#645_

Kate Swetenham
Evaluation of the initial assessment psychosocial clinic – palliative care.  _abs#646_

Shweta Tandon
Posttraumatic growth and its correlates.  _abs#647_
Lili Tang
Barriers to effective decision making in cancer patient.  abs#648

Mélanie Vachon
Existential psychotherapy for total suffering: results of a multiple-case-study research and recommendations for practice.  abs#649

Makoto Wada
Psychiatric services provided by a new department of psycho-oncology established in a public cancer center in Japan: a 2-year review.  abs#650

Cordula Wetzel
Predictors of desire for psychooncological support in breast and gynecological cancer patients.  abs#651

Hayley Whitford
The classification of mobile (cell) phone use as a possible carcinogen: investigating readiness for positive behavioural change in young people.  abs#652

Melinda Williams
The usefulness of the Distress Thermometer in the distress management of cancer patients – a quantitative and qualitative study.  abs#653

Kam Fung Wong
Handling negative emotions by somatic approach – a body work experience.  abs#654

Penny Wright
A randomized pilot study comparing access to the Allograft Information Exchange (ALLINEX) website plus standard care versus standard care for supporting Allogeneic Haemopoietic Stem Cell Transplant (HSCT) patients post transplant.  abs#655

Leonie Young
A partnership providing sustainable health care and support: the breast care nurse and expert peer support.  abs#656

Eun-Seung Yu
A randomized controlled trial of stress management program for breast cancer patients under treatment.  abs#657
Appendix 6.3: Additional publications relevant to thesis

Permission to copy and communicate these works, “Do cancer patients’ psychosocial outcomes and perceptions of quality of care vary across radiation oncology treatment centres?” and “Cancer patients’ concerns regarding access to cancer care: Perceived impact of waiting times along the diagnosis and treatment journey”, has been granted by John Wiley and Sons.
Do cancer patients' psychosocial outcomes and perceptions of quality of care vary across radiation oncology treatment centres?

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Do cancer patients' psychosocial outcomes and perceptions of quality of care vary across radiation oncology treatment centres?

This study aimed to explore whether rates of depression, and anxiety and patient views about quality of patient-centred care varied across four metropolitan radiation therapy treatment centres in Sydney, Australia. Participants were radiation therapy outpatients, aged 18 or older and English-speaking. Participants completed a brief survey by touch screen computer while waiting for their radiation therapy treatment appointment. For eight indicators of patient-centred care, participants were asked to indicate whether their well-being would have been improved by better care related to the indicator. Participants also completed the Hospital Anxiety and Depression Scale. No differences between treatment centres were found for rates of anxiety and depression, or for the mean number of domains of care endorsed as needing improvement (indicated by agreeing or strongly agreeing that their well-being would have been improved by better care). The lack of variance in these outcomes may reflect that variation in treatment centre characteristics does not influence psychosocial outcomes and patient views of their care. Alternatively, it may suggest that the characteristics of the four treatment centres which participated in the present study were too similar for differences in patient outcomes to be observed.

Keywords: cancer, oncology, psychosocial, anxiety, depression, patient-centred care.

INTRODUCTION

Patient-centred care has been broadly defined as care which is responsive to the needs, values and preferences of patients [Gerteis et al. 1993; Institute of Medicine 2001]. Domains commonly identified as important to patient-centred care include: (1) physical comfort; (2) emotional support; (3) respect for patient preferences; (4) integration and coordination of care; (5) information and education; and (6) involvement of family and friends [Institute of Medicine 2001]. There is increasing acceptance of this as a key dimension of quality of care, with several government and non-government organisations developing policy documents and position papers on patient-centred care [Luxford et al. 2010]. Because assessment of the quality of patient-centred care requires a judgment as to how well patient’s needs and preferences were met by the care provided, patients play an essential role in this evaluation process [Stewart 2001; Coulter 2006]. Several countries have introduced patient surveys to evaluate quality in this
domain. The National Health Service in the UK conducts regular surveys of patients to monitor trends in patients’ views about their care over time. One of these surveys specifically focussed on the experiences of people with cancer (Airey et al. 2002). Similarly, in Canada and Australia patient experience surveys have been implemented to examine cancer patients’ views about the quality of their care (Watson et al. 2007; Heading et al. 2008). While results of these surveys generally indicate that patients perceive that their care is good across most domains, the need for improvements in information provision and emotional support are commonly identified (Watson et al. 2007; Heading et al. 2008).

Descriptive studies suggest that there is an association between patient-centred care and outcomes such as better physical health (Fremont et al. 2001), reductions in 1-year mortality among cardiovascular disease patients (Meterko et al. 2010) and receipt of preventive care by Veteran’s Health Administration clients (Flach et al. 2004). Randomised controlled trials indicate that interventions may improve delivery of patient-centred care; however, the extent which these influence patient health behaviours and other health outcomes is not clear (Lewin et al. 2001). In particular, there is little research on this topic of relevance to cancer patients. It is plausible, for example, that hospitals which deliver high-quality patient-centred care may have patients who report lower rates of anxiety, depression, unmet needs and better symptom control than other hospitals. This may be because such needs are anticipated, planned for and addressed in a timely manner within such an environment. Despite this, our recent review failed to identify any studies which examined whether variation in systems, structures or other processes of care between treatment centres influence cancer patients’ psychosocial outcomes (Carey et al. 2011). This study aimed to examine: [1] whether there is variation between cancer treatment centres in number of domains of care which cancer patients report as needing improvement; and [2] whether there is variation between cancer treatment centres in the proportion of patients reporting clinically significant anxiety and depression.

METHODS

Setting

A convenience sample of four radiation oncology treatment centres in metropolitan New South Wales, Australia was recruited. All centres were attached to public hospitals, and had two to four linear accelerators in use. Average patient throughput varied between approximately 60 and 140 patients per day. Ethics approval for the study was gained from the University of Newcastle and Cancer Institute of New South Wales Human Research Ethics Committees.

Participants

Eligible patients were diagnosed with cancer, presenting for a radiation therapy treatment appointment, aged 18 years or older and English-speaking. Participants who were presenting for their first clinic appointment and those who were judged too sick to participate by clinic staff were excluded.

Procedure

A research assistant assessed eligibility for the study and sought informed consent from eligible patients. Consent-seeking patients were asked to complete a 10- to 15-min touch screen computer survey. Questions were presented on screen and participants were instructed to ‘touch’ the response on screen which corresponded to their answer. Results relating to which domains are most frequently endorsed as requiring improvement and disease and socio-demographic variables associated with patients indicating that none of the eight domains of care require improvement will be reported elsewhere.

Measures

Demographic questions

Respondents were asked to indicate their age, gender, postcode, country of birth, health insurance and living arrangements.

Medical variables

Type of cancer, number of weeks’ since diagnosis and whether the person was currently having treatment were assessed by self-report.

Quality of care

An introductory screen to the quality of care questions read ‘Cancer patients have suggested that improvements in some areas of care may improve their well-being. We would like you to tell us which of the following aspects of care (if any) could have been improved since you were diagnosed with cancer. Your answers will be confidential. Your answers may help us to identify areas where care
may be improved'. Perceived quality of care was assessed using the following question stem: 'During my cancer care, my well-being would have been greatly improved by: . . .’. Response options were presented on a 4-point Likert scale (1 = strongly disagree; 4 = strongly agree).

Eight domains of quality of care were assessed with a single question for each: (1) better management of my physical symptoms; (2) better information and communication about my cancer and care; (3) better emotional and/or spiritual support; (4) better services, information and support for my friends/family; (5) better staff approachability and respect for me; (6) getting better access to the care I need when required; (7) better services/support to cope with changes to my relationships; and (8) better services/advice to assist me with practical concerns. An additional sentence describing each of the domains and examples of what might fit under each domain was presented below each item. Items were derived from the Institute of Medicine criteria for delivery of patient-centred care (Institute of Medicine 2001). Domains which were endorsed as needing improvement were summed for each participant. Items were pilot-tested with 67 participants. Minor changes to wording were made to ensure the items were perceived as relevant and easy to understand by the target population.

The Hospital Anxiety and Depression Scale (HADS) was used to assess clinically significant anxiety and depression. A recent review has recommended the HADS as the instrument of choice for assessing psychological morbidity among those with cancer (Luckett et al. 2010). The HADS meets psychometric criteria for internal consistency (Lloyd-Williams et al. 2001), construct validity (Moorey et al. 1991) and discriminant validity (Walker et al. 2007).

While findings are mixed with respect to the optimal cut-off score to define caseness, a score of 8 has been recommended by a previous review (Bjelland et al. 2002) to achieve an optimal balance between sensitivity and specificity (Love et al. 2002). A subscale score of 8 was used in the current study to indicate possible anxiety and depression on the anxiety and depression scales respectively.

RESULTS

Consent rates

A total of 641 participants were assessed for eligibility. Of these, 132 were ineligible primarily because they were non-English speakers or it was their first visit to the treatment centre. Of the 509 eligible patients, 431 consented to participate. Among those consenting to the study, 346 completed the survey, 13 withdrew after starting the survey and 72 were unable to complete the survey due to time constraints. This gave a consent rate of 85% and completion rate of 80%. There was little difference between the four treatment centres in terms of the demographic and disease characteristics of participants (Table 1). The age of participants and the types of cancers seen at each treatment centre were significantly different.

Perceived quality of care

The number of domains perceived by individual participants as needing improvement ranged from 0 to the maximum of 8 with an overall mean of 1.56 (SD = 2.42). There was no significant difference between the mean number of domains identified as needing improvement at...
Table 2. Mean number of domains of care in which better care would have improved patient well-being (by treatment centre)

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Number of respondents</th>
<th>Mean number of domains needing improvement (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>101</td>
<td>1.76 (2.42)</td>
</tr>
<tr>
<td>2</td>
<td>97</td>
<td>1.16 (2.21)</td>
</tr>
<tr>
<td>3</td>
<td>71</td>
<td>1.73 (2.69)</td>
</tr>
<tr>
<td>4</td>
<td>77</td>
<td>1.64 (2.38)</td>
</tr>
<tr>
<td>Total</td>
<td>346</td>
<td>1.56 (2.42)</td>
</tr>
</tbody>
</table>

Table 3. Number and percentage of patients with possible anxiety and depression (by treatment centre)

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Number of respondents</th>
<th>Clinically significant anxiety*, n [%]</th>
<th>Clinically significant depression*, n [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>100</td>
<td>24 [24]</td>
<td>18 [18]</td>
</tr>
<tr>
<td>2</td>
<td>95</td>
<td>24 [25]</td>
<td>16 [17]</td>
</tr>
<tr>
<td>3</td>
<td>71</td>
<td>24 [34]</td>
<td>14 [20]</td>
</tr>
<tr>
<td>4</td>
<td>77</td>
<td>24 [31]</td>
<td>10 [13]</td>
</tr>
<tr>
<td>Total</td>
<td>343</td>
<td>96 [28]</td>
<td>58 [17]</td>
</tr>
</tbody>
</table>

*Hospital Anxiety and Depression subscales score ≥8.

each treatment centre [Kruskal Wallis non-parametric test, $\chi^2 [3] = 5.811$, $P = 0.121$] (Table 2). Furthermore, across each of the eight domains separately, there was no significant difference between treatment centres in the number of participants endorsing each domain. The mean number of domains reported as needing improvement for each treatment centre is presented in Table 2.

Using a HADS cut-off of 8, 28% of patients were classified as having possible anxiety and 17% as having possible depression (Table 3). There was no significant difference between the treatment centres in the number of anxious ($\chi^2 [3] = 2.717$, $P = 0.437$) or depressed participants ($\chi^2 [3] = 1.327$, $P = 0.723$). Rates of possible anxiety and depression are shown for each treatment centre in Table 3.

DISCUSSION

Previous studies with cancer patients have reported rates of possible anxiety between 27% [Moorey et al. 1991] and 48% [Stark et al. 2002] and rates of possible depression ranging between 9% [Moorey et al. 1991] and 20% [Carroll et al. 1993] using a HADS threshold of 8. Therefore, the results of the present study fell within lower end of the prevalence range for anxiety reported by previous studies. Results for depression fell within the middle of the prevalence range reported by studies.

The measure of quality of care used in the present study was new and thus precluded comparison with past studies. Respondents were asked to indicate if better care in each domain would have improved their well-being. Previous research on quality of life has used patient judgements to determine the clinical significance of changes in quality of life over time [Osoba et al. 1998]. While the average number of care domains reported as needing improvement was only one or two, it is possible that indicating the need for improvements in even a single domain may be clinically important.

Contrary to expectations, neither rates of anxiety or depression nor the mean number of care domains reported as needing improvement varied significantly among the four hospitals. The data therefore suggest that while individual variations are evident, variation in perceptions of quality of care and in rates anxiety and depression due to hospital-level causes could be negligible.

How do these results compare to other findings?

While rates of anxiety and depression have been shown to vary by individual factors such as younger age [National Breast Cancer Centre and National Cancer Control Initiative 2003], poor social support [National Breast Cancer Centre and National Cancer Control Initiative 2003], cancer type [Zabora et al. 2001], advanced disease and the experience of more treatment side effects [National Breast Cancer Centre and National Cancer Control Initiative 2003], to our knowledge, no previous research has examined variation in patient-centred care by hospital setting. Hospital-based variation in other indicators of quality of care suggests that variation in patient perceptions of quality of care should be likely. For example, a study conducted via a population-based cancer registry in the Netherlands identified large variation between sites in patterns of care for lung cancer. Some but not all of this variance was explained by teaching status and patient volume, suggesting the need for further exploration [Elferink et al. 2010].

Shultz and colleagues found that timeliness of treatment for lung cancer among veterans was highly variable, with treatment centre characteristics such as treatment in a non-academic clinic, the existence of a specialised diagnostic clinic, leadership beliefs regarding provision of timely treatment and performance of a patient flow analysis associated with a small proportion of the variance [Schultz et al. 2009]. There is also evidence that system-level factors such as continuity of care [McArdle et al. 1996] and mechanisms for encouraging patient questions in medical consultations [Brown et al. 2001] do affect cancer patient psychosocial outcomes. Therefore, it is reasonable to consider whether study limitations may
underlie the lack of hospital-level variation found in the current study.

Potential reasons for lack of inter-hospital variation

Insufficient variation in the sample of hospitals to detect a difference in outcomes

The present study included only four sites, all of which were large public hospitals in metropolitan New South Wales, Australia. Therefore, it is possible that the characteristics of sites (and providers) which might affect quality of care were very similar in this sample. Therefore, future research should include a larger and more diverse sample of hospitals. However, it should be noted that radiation therapy treatment centres such as those involved in the current study are largely restricted to metropolitan areas of Australia, so a diverse range of patients do attend these centres in order to receive treatment. One of the key challenges for future studies examining the role of hospital variables in determining patient perceptions of quality of care is the need to obtain sufficient data from a broad cross section of patients, providers and sites.

Insufficient responsiveness of measures to identify variation between hospitals

The quality of care measure developed for this study has not yet been psychometrically tested. Therefore, it is possible the measure lacked sufficient reliability, sensitivity or breadth to detect differences between hospitals. However, pilot testing of the questions suggested face validity of the items. Furthermore, it is possible that ceiling effects prevented variation in patient views being detected. This explanation does not hold for the failure to detect variation in rates of anxiety and depression using the HADS, given it has been extensively validated in a number of cancer populations (Luckett et al. 2010).

CONCLUSION

In the present study, we examined whether the proportion of patients reporting clinically significant anxiety and depression varied by hospital, and found no significant differences. Similarly, no significant difference was found between the hospitals in the number of domains of quality of care endorsed as needing improvement. This may suggest characteristics of treatment centres such as process of care to not affect psychosocial outcomes. Alternatively, it may suggest that the characteristics of treatment centres in this study were too homogenous for differences in outcomes to be detected. Further research with a larger sample of hospitals will be needed to confirm or refute the present finding. The authors have recently been funded to undertake a larger study examining variation in patient views of quality and psychosocial outcomes across a range of types of hospitals.

ACKNOWLEDGEMENTS

This research was supported by a grant from the Priority Research Centre for Health Behaviour at the University of Newcastle. Dr Carey is supported by a Hunter Medical Research Institute (HMRI) post-doctoral fellowship and Ms Mackenzie’s PhD candidature is supported by a 2009 Professor Jill Cockburn Scholarship. The authors would like to thank Rochelle Smits for assistance with manuscript preparation. We would also like to thank Mr Sundresan Naicker, Ms Jay Roberts and Ms Kelauren Barry for their assistance with data collection for this study. We would also like to acknowledge the staff and patients in the participating radiation oncology treatment centres for their involvement.

REFERENCES


Cancer patients’ concerns regarding access to cancer care: perceived impact of waiting times along the diagnosis and treatment journey


Cancer patients’ concerns regarding access to cancer care: perceived impact of waiting times along the diagnosis and treatment journey

Waiting times can raise significant concern for cancer patients. This study examined cancer patients’ concern levels at each phase of waiting. Demographic, disease and psychosocial characteristics associated with concern at each phase were also assessed. 146 consenting outpatients \( n = 146 \) were recruited from two hospitals in Sydney, Australia. Each completed a touch-screen computer survey, asking them to recall concern experienced regarding waiting times at each treatment phase. Approximately half \( (52\%) \) reported experiencing concern during at least one treatment phase, while 8.9\% reported experiencing concern at every phase. Higher proportions of patients reported concern about waiting times from: deciding to have radiotherapy to commencement of radiotherapy \( (31\%) \); the first specialist appointment to receiving a cancer diagnosis \( (28\%) \); and...
deciding to have chemotherapy to commencement of chemotherapy (28%). Patient groups more likely to report concern were those of lower socio-economic status, born outside Australia, or of younger age. Although a small proportion of patients reported very high levels of concern regarding waiting times, the experience of some concern was prevalent. Opportunities for reducing this concern are discussed. Vulnerable groups, such as younger and socio-economically disadvantaged patients, should be the focus of efforts to reduce waiting times and patient concern levels.

Keywords: cancer patients, health services accessibility, psychosocial aspects, diagnosis, treatment, vulnerable populations.

INTRODUCTION

The importance of access to high-quality cancer care

Cancer is an international health priority and a major cause of morbidity and mortality worldwide (World Health Organisation 2009). Accordingly, the identification of key indicators of high-quality cancer care has received much attention (Organisation for Economic Development and Co-operation 2009; Institute of Medicine 2011). Access to care is a key indicator of quality care, as indicated by its inclusion in key documents assessing care standards (The Royal College of Physicians & The Royal College of Radiologists 1993; New South Wales Health 2003; Health Canada 2004; Agency for Healthcare Research and Quality 2009) and population health monitoring (Andersen 2008). Access to care involves not just the availability of a service, but also the ability to utilise that care (Aday & Andersen 1974). The receipt of timely attention is central to high-quality care in that delays in receiving care may lead to more advanced disease (Mohammed et al., 2011) and subsequently reduced length of life (Richards et al. 1999; Fahmy et al. 2006; Teppo & Alho 2009).

Timely access to cancer care as a measure of quality

A number of authors have explored delays in the processes of cancer care from the first experience of a symptom to the receipt of treatments (Salomaa et al. 2005; Evans et al. 2007; Olesen et al. 2009). These explorations provide a useful framework for conceptualising the patient experience as a series of ‘waiting times’ between crucial treatment phases. Olesen et al. (2009) identified these crucial phases as the time between the:

1. First contact with a primary care provider and initiation of symptom investigation;
2. Initiation of symptom investigation and subsequent referral;
3. Hospital/specialist referral and first hospital/specialist visit; and

Internationally, guidelines or standards in relation to acceptable waiting times for these crucial phases of cancer care vary (The Royal College of Physicians & The Royal College of Radiologists 1993; Department of Health 2000; Manpower and Standards of Care in Radiation Oncology Committee 2000; New South Wales Health 2003). Such guidelines are generally focussed on maximising a patient’s length of life. However, there is a growing emphasis on the need to minimise psychosocial impacts which may be caused by delays in care (Department of Health 2000; Jones et al. 2001; New South Wales Health 2003; Cancer Care Ontario 2008).

The literature has typically focussed on waiting times (delays) which can have a direct impact on disease outcome. Regardless of whether there is medical risk associated with a delay in accessing care, such delays may have an important psychosocial impact on the patient and his or her family. The consumer experience is an important element for assessing the impact of structures and processes in the care pathway (Sanson-Fisher et al. 2009) given that these elements are often not observable to consumers. It has been argued that endpoint measures, such as patient satisfaction with care, represent an external validation of realised access to care (Aday & Andersen 1974). Previous studies have focussed on patient satisfaction (Cancer Institute New South Wales 2009) and actual waiting times (Gorey et al. 2009; Bilimoria et al. 2011) without gaining a clear sense of the level of patient concern which arises as a result of the perception of waiting.

A relatively new approach to assessing the impact of waiting times on patients is to assess the level of concern arising at critical phases of care. Patient concern regarding waiting times may represent a combination of: (1) the actual or perceived medical risk associated with a delay; (2) patient expectations of care and treatment; and (3) the quality of communication about the waiting times provided by health professionals. Despite reported variations...
in acceptable waiting times for care, relatively little attention has been directed towards the patients’ level of concern in relation to the experience of waiting. Studies which have focussed on the patient experience of waiting times have primarily measured patient satisfaction rather than concern (Gesell & Gregory 2004; Absolom et al. 2006; Groff et al. 2008).

Factors potentially associated with patient experiences of timely access to care

Models which conceptualise access to care from the patient’s perspective have identified a range of factors which may be related to actual utilisation of health services, including patient attitudes, socio-demographic characteristics, and structural aspects of treatment centres (Andersen 1995). A number of factors have also been associated with delays in access to cancer care, including greater geographical distance from care (Sowden et al. 1997; Campbell et al. 1999; Jones et al. 2008; Onega et al. 2008; Drury & Inma 2010), income (van Doorslaer et al. 2006), ethnicity (Shi & Stevens 2005) and health insurance (Hoffman & Paradise 2008). Therefore, these factors might also be associated with greater levels of patient concern about such delays.

While the evidence regarding the effect of socio-demographic factors, such as increased distance to care, on disease outcomes is mixed (Sowden et al. 1997; Campbell et al. 1999), equity of patient access is considered an integral part of providing high-quality care (Institute of Medicine 2001). Therefore, an exploration of patient concerns regarding waiting times for treatment and care should also explore the role that socio-demographic factors may play in experiencing such concerns.

Aims

Among cancer patients attending outpatient radiation therapy appointments, this study aimed to identify:

1. The proportion of patients reporting any level of concern regarding the time elapsed between each of:
   - First symptom-related visit to the General Practitioner (GP), and referral to a cancer specialist,
   - Referral to a cancer specialist, and first appointment with the cancer specialist,
   - First appointment with the cancer specialist and receiving a cancer diagnosis,
   - Decision to have surgery and the date of surgery,
   - Decision to have chemotherapy and commencement of chemotherapy;

2. The proportion of patients reporting ‘any’ level of concern for multiple phases of treatment.

3. Associations between demographic characteristics, disease characteristics, and self-reported psychological distress, and reporting any level of concern at each phase of treatment.

METHODS

Design and ethical approval

A cross-sectional, self-report survey regarding cancer care experiences was completed by participants via touch-screen computer. Ethical approval for the study was obtained from the New South Wales (NSW) Population and Health Services Research Ethics Committee and the University of Newcastle Human Research Ethics Committee. Relevant institutional ethics approvals were also obtained.

Sample

Participants were cancer outpatients recruited from radiation therapy treatment units at two hospitals in Sydney, Australia between March and September 2010. Eligible patients were: aged 18 years or older; diagnosed with any type of cancer; and sufficient in English to complete the survey. Patients who were attending the clinic for the first time were excluded, as at least one prior visit was considered necessary in order to answer a number of the items in the wider cancer survey. Patients who were judged by staff as physically or mentally incapable of completing the survey were also excluded.

Procedure

A nurse from each clinic identified eligible patients from daily clinic appointment lists. Patients were then approached by a research assistant (RA) while waiting for their appointment. Consenting participants were asked to complete a survey using a touch-screen computer. The RA explained the survey content and navigation and logged participants onto the survey using a unique ID code. Participants were given the option of resuming the survey after treatment if they were unable to complete it prior to their appointment.
Measures

Previous research (Salomaa et al. 2005; Olesen et al. 2009), best practice guidelines (New South Wales Health 2003) and consultations with oncologists were used to identify significant treatment phases throughout the cancer journey where waiting times may occur. Survey items were revised following pilot testing with 66 cancer outpatients attending radiation clinics over a 2-week period in February 2010. The patient survey was programmed into a Dell touch-screen computer using Digivey survey software. The following modules were embedded within the larger survey.

Level of concern regarding waiting times at each treatment phase  Six items addressing the six treatment phases (outlined in the aims above) were presented, with respondents indicating their recalled level of concern regarding waiting times for each phase.

For example: 'The length of time I waited between my doctor deciding I was ready for surgery and having surgery to remove the cancer was . . .' – Not at all concerning; Slightly concerning; Moderately concerning; or Very concerning. Each item response scale also included a ‘not applicable’ option such as ‘Have not had surgery to remove the cancer’.

Demographic and disease characteristics  Data on: age; gender; postcode; country of birth; health insurance status; living arrangements; cancer diagnosis; cancer recurrence; time since diagnosis; treatment aim; number of outpatient appointments; and number of oncology appointments, were also collected via patient self report. Socio-economic status (SES) was categorised as low, medium or high based on the Socio-economic Index for Areas (SEIFA) (Australian Bureau of Statistics 2006). Geographical location was categorised as urban, regional and rural and was determined by postcode using the Accessibility/Remoteness Index of Australia (ARIA+) (Trewin 2006).

Levels of clinical distress  The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983) was used as a psychometrically rigorous measure of clinically significant distress at the time of the survey. Caseness for anxiety or depression was defined as a score of eight or above on the corresponding subscale of the HADS (Love et al. 2002). HADS subscale scores were included in statistical models as variables which could be potentially associated with levels of reported concern (Moorey et al. 1991; Lloyd-Williams 2001; Keller et al. 2004; Walker et al. 2007).

Statistical analysis

Frequencies, proportions and 95% confidence intervals (CI) were used to describe the demographic characteristics of participants and their levels of concern regarding waiting times, both overall and at each relevant phase of treatment. Chi-square and logistic regression analyses were used to determine associations between patients’: demographic characteristics, disease characteristics and levels of psychological distress, and experiencing concern for each phase of treatment. The following demographic, disease, and distress characteristics were included in the chi-square analysis: gender; SES (SEIFA); geographical location (ARIA+); health insurance; living arrangements; country of birth; treatment aim; time since diagnosis; cancer recurrence; anxiety; and depression. For each phase of treatment, variables with a value of $P < 0.25$ on the chi-square test were retained for inclusion in the logistic regression. Patient age in years was also added to all logistic regressions as a continuous variable. Variables with a value of $P < 0.10$ in the logistic regression were removed, and regressions were rerun with the remaining variables to identify significant associations.

RESULTS

Response rate and demographic characteristics

Of the 246 eligible patients, 218 consented to take part, giving a consent rate of 89%. Of the 218 patients who began answering the questionnaire, 146 completed it giving a completion rate of 67%. Non-completion was primarily due to appointment waiting times being shorter than expected.

The demographic and disease characteristics of participants are presented in Table 1. The age of participants ranged from 19 to 90 years, with a mean age of 60 [SD = 14.1 years]. Almost 70% of patients reported they were unsure whether or not they had a recurrence of their cancer or a secondary cancer diagnosis. One-fifth of patients reported that they lived alone. There were no patients from rural areas, as defined by ARIA+ (Trewin 2006).

Proportion reporting concern at each time period

Any level of concern  As shown in Table 2, the proportion of patients reporting any level of concern (slight,
moderate or very concerned) regarding waiting times varied from 23% to 31% depending on the phase of care. Phases which had the largest proportion of patients reporting concern about the time taken to access care included: [1] from the decision to have radiotherapy, to the commencement of radiotherapy (31%); [2] from the first appointment with the cancer specialist, to receiving a cancer diagnosis (28%); and [3] from the decision to have chemotherapy, to the commencement of chemotherapy (28%).

**Moderate or high levels of concern** Of the patients who expressed concern at each treatment phase, more than half reported they were moderately or very concerned at the following phases: from the decision to have chemotherapy, to the commencement of chemotherapy (55%); from the decision to have surgery, to the date of surgery (52%); and from the first symptom-related visit to the GP, to gaining a referral to a cancer specialist (50%). Slight levels of concern (72% of all patients concerned) were predominant for the waiting time from the first appointment with cancer specialist, to receiving a cancer diagnosis.

**Proportion reporting any level of concern at multiple phases of treatment** Over 50% of participants reported experiencing concern about waiting times at one or more phases of cancer treatment relevant to them. Within those experiencing concern, 17% of individuals (8.9% of all respondents, 95% CI = 5.2–15) reported experiencing concern regarding waiting times at every phase of cancer treatment relevant to them. Forty-three per cent of all respondents (95% CI = 35–51) reported concern at some of the phases of treatment relevant to them, while 48% (95% CI = 40–56) reported concern at none of the phases of treatment they had experienced.

**Associations between some level of concern and demographic, disease, and distress characteristics for each phase of treatment**

**First symptom-related visit to the GP, to referral to a cancer specialist** Four variables had a value of $P < 0.25$ on the chi-square test: time since diagnosis, $P = 0.17$; cancer recurrence, $P = 0.18$; country of birth, $P = 0.06$; and anxiety, $P = 0.16$. However, following logistic regression analysis, no significant association between these variables and concern at this phase of treatment was found.

**Referral to a cancer specialist, to the first appointment with the cancer specialist** No variables had a value of $P < 0.25$ after performing the chi-square test indicating no

Table 1. Participant demographic and disease characteristics (n = 146)

<table>
<thead>
<tr>
<th>Patient demographics</th>
<th>n (%)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>70 (48)</td>
<td>40–56</td>
</tr>
<tr>
<td>Female</td>
<td>76 (52)</td>
<td>44–60</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>50 (34)</td>
<td>27–42</td>
</tr>
<tr>
<td>Prostate</td>
<td>25 (17)</td>
<td>12–24</td>
</tr>
<tr>
<td>Head and neck</td>
<td>13 (8.9)</td>
<td>5.2–15</td>
</tr>
<tr>
<td>Brain</td>
<td>9 (6.2)</td>
<td>3.2–12</td>
</tr>
<tr>
<td>Colorectal/bowel</td>
<td>9 (6.2)</td>
<td>3.2–12</td>
</tr>
<tr>
<td>Other</td>
<td>40 (27)</td>
<td>21–35</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤2 years</td>
<td>122 (84)</td>
<td>77–89</td>
</tr>
<tr>
<td>&gt;2 years</td>
<td>24 (16)</td>
<td>11–23</td>
</tr>
<tr>
<td>Second cancer diagnosis or recurrence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38 (26)</td>
<td>19–34</td>
</tr>
<tr>
<td>No/not sure</td>
<td>108 (74)</td>
<td>66–81</td>
</tr>
<tr>
<td>Stage of treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving treatment</td>
<td>140 (96)</td>
<td>91–98</td>
</tr>
<tr>
<td>Finished treatment</td>
<td>6 (4.1)</td>
<td>1.8–8.9</td>
</tr>
<tr>
<td>Perceived treatment aim</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cure</td>
<td>70 (50)</td>
<td>42–58</td>
</tr>
<tr>
<td>Prevention</td>
<td>58 (41)</td>
<td>33–50</td>
</tr>
<tr>
<td>Palliation</td>
<td>12 (8.6)</td>
<td>4.9–15</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital and/or extras</td>
<td>87 (61)</td>
<td>53–69</td>
</tr>
<tr>
<td>No</td>
<td>56 (39)</td>
<td>31–47</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>108 (74)</td>
<td>66–81</td>
</tr>
<tr>
<td>Other</td>
<td>38 (26)</td>
<td>19–34</td>
</tr>
<tr>
<td>Living arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With others</td>
<td>117 (80)</td>
<td>73–86</td>
</tr>
<tr>
<td>Alone</td>
<td>29 (20)</td>
<td>14–27</td>
</tr>
<tr>
<td>Outpatient visits to clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤10</td>
<td>85 (58)</td>
<td>50–66</td>
</tr>
<tr>
<td>&gt;10</td>
<td>61 (42)</td>
<td>34–50</td>
</tr>
<tr>
<td>Appointments with cancer specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤4</td>
<td>110 (75)</td>
<td>68–82</td>
</tr>
<tr>
<td>&gt;4</td>
<td>36 (25)</td>
<td>18–32</td>
</tr>
<tr>
<td>Socio-economic status*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low/medium</td>
<td>30 (21)</td>
<td>15–29</td>
</tr>
<tr>
<td>High</td>
<td>113 (79)</td>
<td>71–85</td>
</tr>
<tr>
<td>Geographical location†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>118 (83)</td>
<td>75–88</td>
</tr>
<tr>
<td>Regional</td>
<td>25 (17)</td>
<td>12–25</td>
</tr>
</tbody>
</table>

*Socio-economic status was categorised as low (SEIFA Deciles 1–3 or <930), medium (SEIFA Deciles 4–7 or 930 to1012) or high (SEIFA Deciles 8–10 or >1012) (Australian Bureau of Statistics 2006; Linacare 2007).
†Geographical location was categorised as Metropolitan (ARIA+ Index <0.2), Regional (ARIA+ Index 0.2–5.92), or Remote (ARIA+ Index >5.92) (Trewin 2006).
Table 2. Proportion who reported experiencing concerns about the time taken to access each relevant phase of cancer care from diagnosis to treatment

<table>
<thead>
<tr>
<th>Length of time I waited between</th>
<th>No Concern</th>
<th>Concern</th>
<th>Concern by level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n [%], 95% CI</td>
<td>n [%], 95% CI</td>
<td>Slightly n [%], 95% CI</td>
</tr>
<tr>
<td>First symptom-related visit to the GP, to referral to a cancer specialist [n = 121]</td>
<td>91 (75.67–82)</td>
<td>30 (25.18–33)</td>
<td>15 [12,7.6–20]</td>
</tr>
<tr>
<td>Referral to a cancer specialist, to the first appointment with the cancer specialist [n = 133]</td>
<td>102 (77.69–83)</td>
<td>31 (23.17–31)</td>
<td>17 [13,8.1–20]</td>
</tr>
<tr>
<td>Decision to have surgery, to the date of surgery [n = 111]</td>
<td>86 (77.69–84)</td>
<td>25 (23.16–31)</td>
<td>12 [11,6.2–18]</td>
</tr>
<tr>
<td>Decision to have chemotherapy, to the commencement of chemotherapy [n = 71]</td>
<td>51 (72.60–81)</td>
<td>20 (28.19–40)</td>
<td>9 [13,6.6–23]</td>
</tr>
</tbody>
</table>

association between concern at this phase of treatment and patients’ demographic, disease or distress characteristics.

First appointment with the cancer specialist, to receiving a cancer diagnosis Two variables (cancer recurrence, \(P = 0.16\) and country of birth, \(P = 0.02\)) had values of \(P < 0.25\) on the chi-square test. While neither of these variables showed a significant association with concern, the logistic regression analysis did reveal a significant association between patient age and concern. For younger patients, the odds of reporting concern about waiting times from the first appointment with the cancer specialist, to receiving a cancer diagnosis was increased (OR = 1.03, SE = 0.02, \(P = 0.04\), 95% CI 1.00–1.06).

Decision to have surgery, to the date of surgery Following chi-square analysis, five variables had values of \(P < 0.25\) including: SES, \(P \leq 0.01\); geographical location, \(P = 0.07\); time since diagnosis, \(P = 0.14\); cancer recurrence, \(P = 0.13\); and country of birth, \(P = 0.07\). Logistic regression analysis showed that, compared with patients from high socio-economic backgrounds, patients with low to medium SES had almost six times higher odds of reporting concern about waiting times from the decision to have surgery, to the date of surgery (OR = 5.94, SE = 3.44, \(P < 0.01\), 95% CI 1.91–18.46). The odds of reporting concern at this phase of treatment were also three times higher for patients who were not born in Australia, compared with those who were (OR = 3.06, SE = 1.61, \(P = 0.03\), 95% CI 1.09–8.57).

Decision to have radiotherapy, to the commencement of radiotherapy While gender (\(P = 0.11\)), health insurance (\(P = 0.23\)), and living arrangement (\(P = 0.17\)) variables were added to the logistic regression analysis, no associations for reporting concern at this treatment phase were found.

Decision to have chemotherapy, to the commencement of chemotherapy Similarly, country of birth (\(P = 0.05\)) was added to the logistic regression model for this phase of treatment, and although there was a strong association between country of birth and concern, it was not significant at the \(P < 0.05\) level.

DISCUSSION

Concern about waiting times was reported across all phases of treatment

This study is unique in focussing on level of patient concern associated with perceived waiting times for diagnosis or treatment phases. One-fifth of radiation oncology outpatients who participated reported experiencing substantial levels of concern about the time which elapsed between the treatment phases examined. Levels of concern were considered to be moderate to high for about half of those who reported concern. Waiting time related to receiving a cancer diagnosis was the only phase where slight levels of concern were predominantly reported. This is surprising given that previous studies have reported high rates of anxiety while waiting for test results to confirm a cancer diagnosis (Poole 1997; Drageset et al. 2010). There has been considerable attention to communication skills training for oncology professionals to assist in the delivery of bad news (Ellis & Tattersall 1999; Back et al. 2005). Therefore, this finding may reflect that health professionals have greater skills and awareness of the need to provide appropriate reassurance to patients waiting for the results of diagnostic tests than for other phases in the care trajectory.
Patient concern may relate to expectations that any delay will reduce the chances of a positive treatment outcome, along with anxiety regarding expected risks and side effects of treatment. As cancer diagnosis and treatment pathways are often lengthy, multi-staged, physically difficult and uncertain in outcome (Fitch et al. 2003; Clark & Talcott 2006), some level of patient concern may be unavoidable. This might be considered a strong imperative for attempting to minimise any avoidable distress for this population.

**Concern about waiting times was relatively widespread across participants**

Close to half of the sample reported concern at some phase of the cancer diagnosis and treatment pathway, with 8.9% reporting concern at every phase. Therefore, it appears unlikely that concern about waiting times is confined to a subgroup of individuals who are consistently bothered by waiting times. Further, individuals who were categorised as possible or probable cases of anxiety or depression (according to the HADS), were no more likely to report concern about waiting times than those falling below the ‘caseness’ threshold. Consistent with previous findings, it appears likely that factors associated with the experience of waiting (uncertainty combined with the actual length of time) may be the primary drivers of concern, rather than factors intrinsic to the patient or the disease type (Fitch et al. 2003; Sanmartin et al. 2007).

**Which groups appeared to be particularly vulnerable?**

Contrary to our expectations, relatively few associations were identified between disease or socio-demographic factors and levels of concern. Younger patients had slightly higher odds of reporting concern about waiting times from their first appointment with the cancer specialist to receiving a cancer diagnosis. It may be that younger adults are particularly concerned by delays during the diagnostic pathway. Compared with high SES patients, patients of low to medium SES had almost six times higher odds of reporting concern about the time taken to access surgery. The odds of reporting concern about the time taken to access surgery were also three times higher for patients who were born outside Australia, compared with Australian-born patients. Cancer patients have reported a fear of the cancer spreading during the time between diagnosis and surgery (Fitch et al. 2003) and high levels of psychological distress and uncertainty preoperatively (Drageset et al. 2010). Living in a disadvantaged area or being born in another country may present particular difficulties for arranging timely admission for surgery (Thomas et al. 2009). Some variations by SES in median waiting times for elective surgery in Australia have been reported (Australian Institute of Health and Welfare 2010), and migrant groups diagnosed with cancer have been reported to have poorer outcomes than non-migrants (Gotay et al. 2002). These findings suggest the need to explore the source of concerns about waiting times in these groups. Regardless of whether these groups actually wait longer for surgery, there is a need for additional communication, assistance or support to help manage their particular needs during the waiting time leading up to surgery (Coates 1999; Fitch et al. 2003). Inclusion of non-English speaking patients was beyond the scope of the present study. However, given the elevated levels of concern among English speaking patients born outside of Australia, it seems that exploration of the concerns and experiences of non-English speaking patients may be an important area for future investigation. Studies of the concerns of more culturally and linguistically diverse samples which permit a comparison of English and non-English speaking patients levels of concern may be helpful to explore this further (Gotay et al. 2002).

**How might concerns be addressed or minimised?**

One of the primary paths to reducing the concern over waiting times is improvements in referral patterns and treatment booking systems to minimise actual waiting times. For example, NSW Health (New South Wales Department of Health 2011) has waiting time information which is accessible online and by telephone similar to that used in the UK and Canada (Cancer Care Ontario 2008; National Health Service 2011), to assist referring doctors and their patients in choosing the most suitable treatment centre for surgery. Improving information and support options throughout the treatment trajectory is also likely to be important, not least in terms of informing patients at each step how long the wait could or should be, whether the wait is or is not likely to have an impact on their treatment outcome, and avenues for accessing information for any concerns or queries they may have while waiting.

**Limitations**

The study methodology has a number of limitations including a relatively small sample of patients who were receiving radiotherapy at one of two public hospitals in metropolitan NSW Australia. This approach provided limited power to identify associations and to generalise to broader patient groups. It should also be noted that SES was assessed as an ecological (area-based) measure rather
than a more direct assessment of individual-based markers such as household income [Taylor et al. 2001]. The survey also required patients to report on their level of concern retrospectively. Therefore, it is possible that recall bias or the outcomes of treatment may have affected patient evaluation of their level of concern at the earliest phases of diagnosis. It should also be noted that reported level of concern about waiting time may not be directly related to actual time elapsed, which was not recorded for this study.

CONCLUSION

While it is not yet known whether longer waiting times at different phases of the illness trajectory are associated with poorer clinical or psychosocial outcomes, cancer outpatients express concerns associated with waiting times across almost every care phase from pre-diagnosis to treatment. Patient self-reported concern about waiting times provides an endpoint assessment of an important aspect of quality of care. Further investigations of the factors which underlie these concerns are warranted to understand and intervene in a manner which minimises distress to this very vulnerable patient group.

ACKNOWLEDGEMENTS

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Appendix 7: Study Ethics Approvals
Appendix 7.1: University of Newcastle Certificates of Human Research Ethics Approval
HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL TO CONDUCT HUMAN RESEARCH

To Chief Investigator or Project Supervisor: Laureate Professor Robert Sanson-Fisher
Co-Investigators / Research Students:
Ms Lisa MacKenzie
Professor Catherine d’Este
Mr Ryan Courtney
Mr Sundran Naicker
Professor Rynyn Ward
Doctor Marko Carey
Associate Professor Christine Poul

Re Protocol: Assessing patient views on the quality of cancer care
Date: 25 Jul 2013
Reference No: H.2009.0283

Thank you for your recent application to the University of Newcastle Human Research Ethics Committee (HREC) for approval of the protocol identified above.

Details of previous approvals for Initial, Renewal and Variation applications are available upon request.

A Certificate of Approval is enclosed.

THE CERTIFICATE AND THIS ADVICE ARE TO BE RETAINED THEY ARE IMPORTANT DOCUMENTS

- Note any comments related to the approval.
- Where the HREC is the lead or primary HREC, if the research requires the use of an Information Statement, ensure the Reference No. is inserted into the complaints paragraph in the approved document(s) prior to distribution to potential participants.
- Where the research is the project of a higher degree candidate, it is the responsibility of the project supervisor to ensure that the candidate receives this approval advice.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below.

PLEASE NOTE:
In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, you will apply to the External HREC for approval in the first instance and then Register that approval with the University’s HREC.
Monitoring of Progress

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. The Certificate of Approval identifies the period for which approval is granted and your progress report schedule. A progress report is required on an annual basis, you will be advised when a report is due.

* Reporting of Adverse Events

1. It is the responsibility of the person first named on the Certificate to report adverse events.

2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.

3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Certificate to the (HREC) by way of the Adverse Event Report form within 72 hours of the occurrence of the event or the investigator receiving advice of the event.

4. Serious adverse events are defined as:
   - Causing death, life-threatening or serious disability.
   - Causing or prolonging hospitalisation.
   - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
   - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
   - Any other event which might affect the continued ethical acceptability of the project.

5. Reports of adverse events must include:
   - Participant’s study identification number;
   - date of birth;
   - date of entry into the study;
   - treatment arm (if applicable);
   - date of event;
   - details of event;
   - the investigator’s opinion as to whether the event is related to the research procedures; and
   - action taken in response to the event.

6. Adverse events which do not fall within the definition of serious, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

* Variations to approved protocol

If you wish to change, or deviate from, the approved protocol, you will need to submit an Application for Variation to Approved Human Research. Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. Variations must be approved by the (HREC) before they are implemented except when registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

**Linkage of ethics approval to a new Grant**

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.
With best wishes for a successful project.

Professor Allyson Holbrook  
Chair, Human Research Ethics Committee

For communications and enquiries:  
Human Research Ethics Administration

Research Services  
Research Integrity Unit  
The Chancellory  
The University of Newcastle  
Callaghan NSW 2308  
T: +61 2 492 18888  
F: +61 2 492 17164  
HumanEthics@newcastle.edu.au


Linked University of Newcastle administered funding:

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HUMAN RESEARCH ETHICS COMMITTEE  
Certificate of Approval

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<th>Laureate Professor Robert Sanson-Fisher</th>
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| Co-Investigators / Research Students: | Ms Lisa MacKenzie  
Ms Catherine d’Este  
Mr Ryan Courtney  
Mr Sundar Naicker  
Professor Robyn Ward  
Doctor Miroko Casey  
Associate Professor Christine Paul |

Protocol: Assessing patient views on the quality of cancer care

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Note: Approval is granted subject to the requirements set out in the accompanying document Approval to Conduct Human Research, and any additional comments or conditions noted below.

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Approval
**Progress reports due:** Annually. If the approval of an External HREC has been "noted", the reporting period is as determined by that HREC.

**Approval Details**

**Initial Application**
18-Nov-2009
Approved

**Variation**
17-Feb-2010
Variation to amend the following study documents as per the requirements of the South Eastern Sydney Illawarra Area Health Service - Northern Sector HREC:
1. Participant Information Statement and Consent Form (v3, dated 24/11/09);
2. Appendix B - Survey Document (v3, dated 24/11/09);
3. Appendix C - Survey modules and study outline (v1, dated 24/11/09).
Approved
The Committee ratified the approval granted by the Chair on 17 December 2009 under the provisions for expedited review

**Variation**
21-Jul-2010
Variation to:
1. Extend the source of recruitment from just medical oncology clinics to all types of cancer clinics (excluding palliative care) at participating hospitals.
2. Amend the Quality of Care Survey 1 (now v7, dated 26/05/2010) as follows:
   a. Demographic items - formatting changes, addition of 2 new items and removal of several others;
   b. Quality of Care items - wording changes as a result of participant feedback from initial sample;
   c. Life Expectancy Information Items - inclusion of a definition of life expectancy, addition of several items to assess whether current practice and patient preferences align with consensus guidelines available in the area of prognosis disclosure, and provision of additional response options for Q7;
   d. Emotional Response to Cancer Diagnosis Items - two items added to gauge participant's emotional responses to their cancer diagnosis;
   e. Emotional Distress Items - questions regarding anxiety and depression modified or removed and replaced with items covering both level of anxiety/depression and desire for professional help and acceptability of various forms of professional assistance;
   f. Family History Screening Module (colorectal cancer patients only) - minor formatting and other changes made to allow for more thorough investigation of the research area and ease participant understanding of study area, and
   g. Removal of acceptability of touchscreen computer items - were only required in the pilot phase.
3. Conduct a sub-study involving 400 of the originally planned 1,000 participants to assess additional issues in quality of care. This sub-group of participants will receive the Quality of Care Survey 2 (v2, dated 26/05/2010). Survey 2 will seek to explore participant experiences and preferences for types of assistance with decision making, preparation for threatening medical procedures and further examination of general quality of care issues. Survey 2 will differ from Survey 1 as follows:
   a. Quality of Care Items - additional questions to elicit details of how care might be improved and about the consistency of information received;
   b. Addition of a section on Decision Making processes;
   c. Addition of a section on Threatening Medical Procedures;
4. Amend or introduce the following study documents to reflect the above:
   a. Information Statement and Consent Form (v5, dated 30/04/10), and

b. Information Statement and Consent Form for Survey 2 (v1, dated 30/04/10).
Approved
The Committee ratified the approval granted by the chair on 18/05/10 under the provisions for expedited review.

**Variation**
19-May-2010
Variation to:

1. Add Ms Amy Anderson to the research team as a PhD student researcher.
2. Delete Ms Tara Clinton-McHarg from the research team.
3. Amend the Cancer Care Survey (now v5, dated 16/03/2010) by reducing the number of survey items and simplifying the response format. The time for completing the survey is now 13-20 minutes.
4. Amend the Participant Information Statement (now v4, dated 16/02/2010) to reflect the above.
5. Amend the section of the Consent Form for Future Research (now v4, dated 16/02/2010) to provide more information about the survey and to simplify the question about the number of times a participant is willing to be contacted in a year.
Approved
The Committee ratified the approval granted by the Chair on 16/04/10 under the Provisions for expedited review.

**Variation**
06-Dec-2010
Variation to:

1. Amend the research team as follows:
   a. Addition of Mr Sundreesh Naicker, and
   b. Deletion of Miss Amy Anderson.
2. Amend the study surveys as follows.
   a. Quality of Care Survey 1:
      i. Changes to life expectancy module;
      ii. Deletion of general emotional response to diagnosis & current feelings questions; and
      iii. Changes to anxiety and depression treatment preference questions.
   b. Surveys 1 & 2 - Changes to the family history screening module.
3. Remove the 'willingness to be contacted in the future' consent process.

- Information Statement - Survey 1 (v7, dated 12/10/2010)
- Survey 1 (v6, dated 12/10/2010)
- Survey 2 (v4, dated 12/11/2010)
Approved
The Committee ratified the approval granted by the Chair on 26/11/10 under the Provisions for expedited review.

Authorised Certificate held in Research Services

Professor Allyson Holtbrook
Chair, Human Research Ethics Committee

Appendix 7.2: University of Newcastle Safety Clearance Notification
From: Natasha Cooper
To: Rob Sanson-Fisher
CC: Chris Paul; Judy Alexander; Lisa Mackenzie; Liz Pilgrim; Mariko Carey
Date: 6/11/2009 3:47 pm
Attachments: SME Evaluation off-site_SansonFisher2222009.docx

Re: Sanson-Fisher 222/2009 "Assessing patient views on the quality of cancer care"
Funding bodies: Jill Cockburn Scholarship in Health Behaviour; Rotary Bowel Scan Scholarship

Please be advised that this Off-site Activity has been granted safety clearance. Note; if there is any variation to the protocol that affects the safety outcomes an additional application for safety clearance is necessary.

Attached is a copy of the Off-site SME Evaluation.

If you have any enquiries in relation to this safety clearance please do not hesitate to contact Natasha Cooper, Senior Safety Officer ext. 16846 or natasha.cooper@newcastle.edu.au

Natasha Cooper
Senior Safety Officer - Laboratory/Research
Health, Safety and Environment Team
University of Newcastle

Phone: 61 (0)2 492 16846
Mobile: 61 (0)431 375424
Natasha.Cooper@newcastle.edu.au

Please consider the environment and only print this if absolutely necessary. Thank you.
Appendix 7.3: University of Newcastle Health, Safety & Environment Evaluation Report
### Health Safety and Environment Evaluation Report

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### Section A

1. **Names of principal investigators.**

   Laureate Professor Rob Sanson-Fisher, Dr Mariko Carey, Dr Chris Paul, Ms Lisa Mackenzie, Mr Ryan Courtney, Tara Clinton-McHarg

2. **Project title.**

   Assessing patient views on the quality of cancer care.

3. **Reference no.**

   222/2009
4 The following information has been checked and approved (please tick):
If insufficient information has been provided, email the principal investigator with a request to provide the required information.

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<td>(i) Higher Risk activities: Abseiling, Scuba Diving, etc</td>
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<td>(j) The risk assessment and risk management.</td>
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<td>(k) Authorised by HOS</td>
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## HOME VISIT / FOCUS GROUPS

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<th>(a) Description</th>
<th>(b) Dates and time involved</th>
<th>(c) Location</th>
<th>(d) DFAT rating</th>
<th>(e) Private property/public area approvals</th>
<th>(f) Human/Animal Ethics Human</th>
<th>(g) Travel policy</th>
<th>(h) The risk assessment and risk management.</th>
<th>(i) Appendix 7.1 of guideline</th>
<th>(j) Appendix 7.2 of guideline</th>
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### 5

The training and experience of the project team for carrying out this type of work are considered adequate.

### 6

Assessment.
The following is a brief description of the project protocol with any additional conditions that must be adhered to during the conduct of the work:

- Appendices 7.1 and 7.2 attached as risk assessment.
- PhD candidate has completed “Prevention & Management of Violence & Aggression (PMVA)” Course
Complete this section for all categories of work:

This proposal has been assessed as above. The following conditions must be adhered to during the conduct of the work:

As post-graduate students will be working on their own at times, please draw up a schedule of when candidates will be working on the survey at the hospital and clinics. Keep it up-to-date and ensure Chief Investigator and other Alternate Contacts always have a copy. This is a precaution to enhance candidate’s offsite security while working on the project.

Name of SME: Ms Natasha Cooper, SSO (Laboratory/Research)

06/11/2009
Appendix 7.4: South Eastern Sydney and Illawarra Area Health Service
Certificates of Human Research Ethics Approval
Dear Prof. Sanson-Fisher,

HREC Reference Number: 09/137
Project Title: Project title: Assessing patient views on the quality of cancer care

Thank you for submitting the above project which was first considered by the Human Research Ethics Committee (HREC) of the Northern Hospital Network at its meeting held on 29 September 2009.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans and the CPMP/ICH Note for Guidance on Good Clinical Practice.

At that meeting the HREC requested that the investigator respond to their points for further clarification and resubmit an amended Participant Information Statement and Consent Form and Survey. The HREC delegated final approval to the HREC Executive Officer if the revised documents were updated as recommended.

I am pleased to advise that with your letter dated 19 November 2009 the requested information and revised documents were received incorporating the recommendations of the Executive. Ethical approval has been granted for the above project to be conducted at the Prince of Wales Hospital and at the St George Hospital.

The following documentation has been reviewed and approved by the HREC:

- NEAF, dated 28 August 2009, locked code AB/13060/1
- Study Protocol, version 1, dated 28 August 2009
- Participant Information Statement, version 2, dated 18 November 2009
- Quality of Care Survey, version 2, dated 17 November 2009
Please note the following conditions of approval:

1. This approval is valid for five years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in December 2010.

2. The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by study participants regarding the conduct of the study.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review, in the specified format.

4. The HREC will be notified, giving reasons, if the project is discontinued before the expected date of completion.

5. The Co-ordinating Investigator will provide a progress report, in the specified format, annually to the HREC as well as at the completion of the study.

HREC approval is valid for 5 years from the date of this letter.

Optional Please note it is the responsibility of the sponsor or the principal (or co-ordinating) Investigator of the project to register this study on a publicly available online registry (e.g. Australian New Zealand Clinical Trials Registry www.anzctr.org.au).

You are reminded that this letter constitutes ethical approval only. You must not commence this research project until you have submitted your Site Specific Assessment to the Research Governance Officer of the appropriate Institution and have received a letter of authorisation from the General Manager or Chief Executive of that Institution.

Should you have any queries about your project please contact the Human Research Ethics Secretariat, Research Support Office, Ext: 9362-3357. The HREC Terms of Reference, Standard Operating Procedures and membership are available from the Research Support Office.

Please quote HREC Ref No.06/137 in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely,

Deborah Adrian
Executive Officer, Human Research Ethics Committee
HREC – NHMRC
Appendix 7.5: Cancer Institute NSW Certificates of Human Research Ethics Approval
Prof Rob Sanson-Fisher  
Health/ Medicine and Public Health  
Rm 267, David Maddison Clinical Science Building  
The University of Newcastle  
Callaghan NSW 2308

24 March 2010

Dear Prof Sanson-Fisher,

NSW Population & Health Services Research Ethics Committee

AU RED Reference: HREC/10/CIPHS/7

Cancer Institute NSW reference number: 2009/12/209

Project Title: “Assessing patient views on the quality of cancer care”.

Thank you for your correspondence dated 23 Feb 2010 responding to a request for further information/ modification to the above referenced study, submitted for single ethical review by the NSW Population & Health Services Research Ethics Committee. The Committee reviewed your documentation at its meeting held on 22 Mar 2010, and I am pleased to inform you that full ethical approval of this project has been granted.

The following documents were reviewed during the Committee’s deliberation of the study:
- National Ethics Application Form version 2, lock code AB/14739/1 dated 18/11/2009
- Letter of reply 23 Feb 2010
- NSW Privacy form
- Study Protocol, version 1, dated Nov 2009
- Participant Information Statement, version 2, dated 23 Feb 2010
- Quality of Care Survey, version 2, dated 23 Feb 2010
- SESIAHS HREC approval letter, dated 7 Dec 2009
- Change of personnel form, dated 23 Feb 2010 – Amy Anderson, POW Hospital and St George Hospital

Approval is valid for the following sites:
- Prince of Wales Hospital
- St George Hospital

COMMENT: Approval from this HREC is for the pilot study only.

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.
The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) and relevant legislation and guidelines.

Please note that ethical approval is valid for a period of 5 years from the approval date, conditional on the following:

- Principal investigators will immediately report anything which might warrant a review of ethical approval of the research, including unforeseen events that might affect continued ethical acceptability.
- Proposed amendments to the research proposal or conduct of the research which may affect the ethical acceptability of the research are to be provided to the NSW Population & Health Services Research Ethics Committee for review.
- The NSW Population & Health Services Research Ethics Committee will be notified giving reasons, if the research is discontinued before the expected date of completion.
- The Principal Investigator will provide an annual progress report to the NSW Population & Health Services Research Ethics Committee and at the completion of the study.

For further information about the NSW Population & Health Services Research Ethics Committee please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal please contact Marion Marson, Admin Support Officer - Ethics on 02 8374 3582 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Sharon Fellew
Ethics Coordinator
Cancer Institute NSW
NSW Population & Health Services Research Ethics Committee
Prof Rob Sanson-Fisher  
Health/Medicine and Public Health  
Rm 267, David Maddison Clinical Science Building  
The University of Newcastle  
Callaghan NSW 2308

28 July 2010

Dear Prof Sanson-Fisher,

NSW Population & Health Services Research Ethics Committee

AU RED Reference: HREC/10/CIPHS/7

Cancer Institute NSW reference number: 2009/12/209

Project Title: Assessing patient views on the quality of cancer care

Thank you for your recent correspondence requesting changes to the above referenced study, submitted for review to the NSW Population and Health Services Research Ethics Committee. The Committee reviewed the amendment documentation at its meeting held on 16 Jul 2010 and has granted ongoing ethical approval.

The following documents have been approved for this amendment:

- CI NSW Request for Amendment form dated 28 Apr 2010
- Cover letter, dated 2 Jul 2010
- Addition of site: Concord Repatriation Hospital, Prof Stephen Clarke
- Addition of site: Royal Prince Alfred Hospital, A/Prof Chris Milross
- Addition of site: Royal North Shore Hospital, Dr William Stevenson

This approval is valid for the following sites in total:

- Prince of Wales Hospital
- St George Hospital
- Royal Prince Alfred Hospital
- Royal North Shore Hospital
- Concord Repatriation Hospital

*PLEASE NOTE*
All papers for review must be submitted as a complete set.
To facilitate the progress of amendments and new applications please include all papers in one set of correspondence. If you have a Cancer Institute reference number this must also be cited in all correspondence.
The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.

The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) and relevant legislation and guidelines.

For further information about the NSW Population & Health Services Research Ethics Committee please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal please contact Marion Marson, Admin Support Officer - Ethics on 02 8374 3562 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Sharon Falleiro
Ethics Coordinator
Cancer Institute NSW
NSW Population & Health Services Research Ethics Committee
Prof Rob Sanson-Fisher  
Health/ Medicine and Public Health  
Rm 267, David Maddison Clinical Science Building  
The University of Newcastle  
Callaghan NSW 2308

1 December 2010

Dear Prof Sanson-Fisher,

NSW Population & Health Services Research Ethics Committee

AU RED Reference: HREC/10/CIPHS7

Cancer Institute NSW reference number: 2009/12/209

Project Title: Assessing patient views on the quality of cancer care

Thank you for your recent correspondence requesting changes to the above referenced study, submitted for single ethical review to the NSW Population & Health Services Research Ethics Committee. The Committee reviewed your documentation at its meeting held on 18 Nov 2010, and has granted ongoing ethical approval.

The following documents were reviewed during the Committee’s deliberation of the study:

- CI NSW Request for Amendment form, dated 5 Oct 2010
- Survey 1, version 4, dated 30 Sep 2010
- Information sheet, version 4, dated 30 Sep 2010
- Survey 2, version 2, dated 30 Sep 2010
- Information sheet survey 2, version 2, dated 30 Sep 2010
- Change of personnel form – removal of Miss Amy Anderson from the study, dated 5 Oct 2010

This approval is valid for the following sites:

- Prince of Wales Hospital
- St George Hospital
- Royal Prince Alfred Hospital
- Royal North Shore Hospital
- Concord Repatriation Hospital

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.

The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the...
National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) and relevant legislation and guidelines.

For further information about the NSW Population & Health Services Research Ethics Committee please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal please contact Marion Merson, Admin Support Officer - Ethics on 02 8374 3562 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Sharon Falleiro  
Ethics Coordinator  
Cancer Institute NSW  
NSW Population & Health Services Research Ethics Committee
Appendix 7.6: Hospital site-specific approvals
7.6.1: Approval from Prince of Wales Hospital
7 January 2010

Professor Robyn Ward
Medical Professorial Unit
Prince of Wales Hospital
RANDWICK NSW 2031

Dear Professor Ward

RE: SSA Ref: 09/G/201
HREC / All RED Ref: 09/137
Project Title: Assessing patient views on the quality of cancer care.

I refer to your Site Specific Assessment application for the above titled project. I am pleased to advise that on 7 January 2010 the Acting General Manager Northern Hospital Network granted authorisation for the above project to commence at the Prince of Wales Hospital.

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

If you have any queries relating to the above please contact the Research Support Office on 9382 3687.

Yours sincerely

Ms Marie Malica
Manager, Research Support Office
Research Governance Coordinator
7.6.2: Approval from St George Public Hospital and Sutherland Hospital

13 April 2010

Dr Chee Khoon Lee
Division of Cancer Services
Ground Floor, W.R.Pitney
Clinical Sciences Building
St George Hospital
Kogarah NSW 2217

Dear Dr Lee

HREC reference number: HREC/10/CIPHS/7
SSA reference number: SSA/10/STG/43
Project title: Assessing patient views on the quality of cancer care
Collaborative Group: University of Newcastle

Thank you for submitting an application for authorisation of this project.

I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- St George Public Hospital
- The Sutherland Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee (HREC) that granted ethical approval:

1. Please advise Research Management Office of the project commencement date
2. It is expected that PD2009_018 Waiting Time and Elective Patient Management Policy is adhered to for the duration of the project
3. All parties involved will comply with the guidelines and recommendations associated with Highly Specialised Drugs and the Pharmaceutical Benefits Scheme (PBS) criteria for patients
4. Any examinations completed over and above Standard Patient Treatment will be covered by the cost centre allocated to this project
5. Proposed amendments to the research protocol which may affect the ethical acceptability of the project, that are submitted to the lead HREC for review, should be copied to the site Research Governance Officer
6. Proposed amendments to the research study or personnel which may affect the ongoing site acceptability of the project, should be submitted to the site Research Governance Officer

Yours faithfully

Lisa Stanton
Research Governance Officer
Central Hospital Network

cc.

☐ Prof Michael Grimm – St George Clinical School
☐ Vivienne Rowlands - Medical Records
☐ Angelika Flemetakis - Finance / Revenue
☐ Ms Kim Rigg – TSH Oncology
Appendix 7.6.3: Approval from Royal North Shore Hospital
06/10/2010

Dr R Sanson-Fisher
Locked Bag 10
Wallsend
2287
NSW

Dear Dr Sanson-Fisher,

Re: SITE SPECIFIC ASSESSMENT (SSA) APPROVAL

PROTOCOL- 1005-170M, (Other - II)

AURED NEAF REF: HREC/10/CIPHS/7
AURED SSA REF: SSA/10/HAWKE/52

STUDY INVESTIGATORS: Dr R Sanson-Fisher, Dr William Stevenson
STUDY TITLE: Assessing patient views on the quality of cancer care

I am pleased to inform you that on the 6 October 2010, the delegate of the Chief
Executive authorised the Site Specific Assessment for the above study on behalf of
Northern Sydney Central Coast Health (NSCCH).

It is noted that the approval covers the following NSW Health site:

- Royal North Shore Hospital

The documentation included in the approval is as follows:

- Lead HREC approval letter dated 24 March 2010
- National Ethics Application Form version 2, dated 18 November 2009, AB/14739/1
- Letter of reply dated 23 February 2010
- NSW Privacy Form
- Study Protocol, version 1, dated November 2010
- Participant Information Sheet, version 2, dated 23 February 2010
- Quality of Care Survey, version 2, dated 23 February 2010
• SESIAHS HREC approval letter, dated 7 December 2009
• Change of personnel form, dated 23 February 2010
• Site Specific Assessment Form, Version 1, dated 19 April 2010, AU/14739/25760/2/222/27815/8169

It is noted that the Ethical & Scientific Approval for this project was reviewed and approved by Cancer Institute NSW – Population & Health Services Research Ethics Committee who is accredited under the NSW Health model for single ethical review of multi-centre research.

At this time, we also remind you that, in order to comply with the Guidelines for Good Clinical Research Practice (GCRP) in Australia, and in line with NSCCH HREC policy, the Chief Investigator is responsible to ensure that:

1. The HREC is notified of anything that might warrant review of the ethical approval of the project, including unforeseen events that might affect the ethical acceptability of the project.
2. The HREC is notified of all Serious Adverse Events (SAEs) or Serious Unexpected Suspected Adverse Reactions (SUSARs) in accordance with the Serious Adverse Event Reporting Guidelines. Please refer to the Research Office website.
3. Proposed amendments to the research protocol or conduct of the research that may affect the ethical acceptability of the project are submitted to the HREC on an amendment form (including any relevant attachments). For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each of the sites so that they can notify their Research Governance Officer.
4. The HREC must be provided with a final report upon completion of the study. For multi-centre studies the Chief Investigator should notify the Lead HREC and the investigators at each site should notify the relevant Research Governance Officer.

Please refer to the NSCCAHS Research Office website to access forms such as the amendment form, Annual/Final Report Form, Change in Personnel Form and Serious Adverse Event Guidelines and Forms:

Intranet:

Approval lasts for four years; therefore, your approval will expire on 6/10/2014. Should you require an extension an amendment form should be submitted.

Yours sincerely,

Ellaina Speziale

Ethics Officer

Research Office

NORTHERN SYDNEY CENTRAL COAST HEALTH
7.6.4: Approval from Royal Prince Alfred Hospital
1 November 2010

A/Professor C Milross
Department of Radiation Oncology
Building 27
Royal Prince Alfred Hospital

Dear Professor Milross,

Re: Protocol No X10-0141 - “Assessing patient views on the quality of cancer care”

HREC/10/CIPHS/7

Thank you for submitting a Site Specific Assessment Form for this study. I am pleased to inform you that authorisation has been granted for it to be undertaken at the Royal Prince Alfred Hospital.

The approved information and consent documents for use at this site are:

- Participant Information Statement – Survey 1 (RPAH Version 1, 17 June 2010)
- Consent Form for the Research Project– Survey 1 (RPAH Version 1, 17 June 2010)
- Participant Information Statement – Survey 2 (RPAH Version 1, 17 June 2010)
- Consent Form for the Research Project– Survey 1 (RPAH Version 1, 17 June 2010)

The following conditions apply to this research study. These are additional to those conditions imposed by the human research ethics committee (HREC) that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the study and which are submitted to the lead HREC for review, must be copied to me.
2. Proposed amendments to the research protocol or conduct of the research, which may affect the ongoing site acceptability of the study, must be submitted to me.

I wish you every success in your research.

Yours sincerely,

Lesley Townsend
Research Governance Officer
SSWAHS (RPAH Zone)

RGO - Lesley/CORRES/X10-0141
Appendix 8: Hospital Anxiety and Depression Scale
Granada Learning

**Invoicing Details**

**INVOICE TO:**
Account No 122274
The University Of Newcastle
Room 286 David maddison Clinical Science Building School Of Medicine & Public Health
University Drive
Newcastle Upon Tyne

**DELIVER TO:**
Account No 122274
Dr Mariko Carey
The University Of Newcastle
Room 286 David maddison Clinical Science Building School Of Medicine & Public Health
University Drive
Culcheth

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**Invoice Details**

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**Remittance Advice Slip**

Please detach and include with payment.

**Our Invoice Ref:** 752230
**Our Invoice Date:** 17 Nov 09
**Our Order Ref:** DRMARIKOCAREY01711

**Payment Accepted via Cheque, Credit Card or BACS.**

Cheques made payable to Granada Learning Ltd.
BACS: Barclays Bank Plc
A/C No: 10435317
Sort Code: 20-78-98
IBAN: GB 32 BARO 9910 4353 17

**Our standard terms are 30 days, please settle invoice by 17 Dec 09**

Balance Outstanding: £306.95

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**Appendix 8.1: Hospital Anxiety and Depression Scale permission invoice**
Appendix 9: Standardised Study Procedures and Materials
Appendix 9.1: Research Assistant Recruitment Manual
ASSESSING PATIENT VIEWS ON THE QUALITY OF CANCER CARE

TOUCHSCREEN COMPUTER SURVEY

Participant Recruitment Manual

Version 1, 5th July 2010
1. Introduction

This manual is designed to provide you with information regarding the “Assessing patient views on the quality of care” project that we are conducting. This manual clearly outlines the study procedures and your role in participant recruitment. This manual should be referred to throughout the entire duration of the project.

Your role in recruiting participants for the project is crucial to the process of data collection. The data collected are very important in helping us determine whether using a computer-based system is a feasible and acceptable way to assess cancer patient views of care.

As part of participant recruitment, you will be responsible for providing relevant information regarding the study to participants, ensuring participants’ privacy is protected, and assisting participants with completing the survey.

This manual has been developed to assist you in doing these tasks. Please retain this manual for your future reference.

If you have any suggestions for changes or additions to this manual, please contact Lisa Mackenzie (Lisa.Mackenzie@newcastle.edu.au).
2. Study background

A growing mandate to provide patient-centred cancer care

The Institute of Medicine has set six objectives for achieving optimal health care. These relate to improving the safety, effectiveness, timeliness, patient-centredness, efficiency and equity of care.\textsuperscript{1} The prominence of patient-centred care within this definition of quality acknowledges that while healthcare aims to cure where possible, it should always aim to relieve suffering.\textsuperscript{1} Patient-centred care must: a) be responsive to consumer needs, values and preferences; b) be integrated and co-ordinated; c) relieve physical discomfort; d) provide emotional support; e) allow for the involvement of family and friends; and f) support the provision of information, communication and education to enable patients to understand and make informed decisions about their care and manage the effects of their condition.\textsuperscript{1, 2}

The role of consumers in shaping patient-centred care

Patient-centred care is best assessed by asking patients to report on their experiences of care.\textsuperscript{3} While there is debate about the accuracy with which patients recall specific aspects of care provided, patients' views about their care should not be devalued.\textsuperscript{3} A judgement regarding quality of healthcare must consider not just whether care was provided, but whether the method of delivery enables patients to understand, recall and apply knowledge about their condition.\textsuperscript{4} If this is not the case, it is unlikely that information provided will assist the patient in improving their well-being. Consequently, it is accepted that consumers' views about whether care was received and was helpful, represent an essential component when assessing quality of care.\textsuperscript{3, 5} Further, it is recognised that consumers have an important role to play in setting agendas for healthcare research, policy and practice.\textsuperscript{6} Therefore, it is important to develop effective mechanisms for collecting consumer perceptions of the quality of their care. This information provides a powerful tool to stimulate quality improvement activities. It is consistent with patient-centred care, providing an opportunity for consumers to play an active and legitimate role in shaping the healthcare system.

How patient-centred is cancer care?

Two recent, large-scale efforts have attempted to assess quality of cancer care from a patient-centred perspective. The first was a patient satisfaction survey administered by the New South Wales Cancer Institute in partnership with New South Wales Health. Patients reported high levels of satisfaction in relation to being treated respectfully and the overall attitudes of staff. However, lower satisfaction was reported in areas of care pertaining to provision of emotional support and information.\textsuperscript{7} The validity of these
results is threatened by several factors: sampling of public patients only; and use of satisfaction as the primary measure. Reviews of the satisfaction literature reveal conceptual and methodological concerns. Satisfaction is influenced by multiple factors, including the care provided, patient needs and patient expectations; however, the exact influence of these factors is difficult to assess. Satisfaction may reflect a patient’s view that an attempt was made to help, rather than whether a benefit was received. Systematic biases occur, in that older patients generally report greater satisfaction than younger patients. These issues may result in difficulties interpreting and using data on cancer patients’ satisfaction with care.

Consequently, the Cancer Council Victoria’s PROSPECT Program (Patient Responses: An Ongoing Survey of People Experiencing Cancer Treatment) has focused on measuring cancer patients’ perceptions of their experiences of care. The program piloted a different measurement strategy, obtaining a representative sample through the Victorian Cancer Registry. Preliminary results indicate marked variations in patient perceptions of care across geographic regions. Due to the registry-based recruitment mechanism, participants were recruited 5-6 months’ post diagnosis. This is likely to reduce accuracy of perceptions of the care provided during diagnosis and treatment planning.

What are cancer patients willing to do to help others with cancer?

People who have experienced cancer can have a positive impact on improving cancer services for others by sharing their own views and experiences of cancer care through participation in surveys, discussion groups and direct support for other patients. There is a need to provide cancer patients with an opportunity to indicate their willingness to assist others with cancer through research participation, as it is thought that the process of involvement in research may be empowering for cancer patients. Once this information is collected, it will allow researchers to be responsive to cancer patients’ preferences for involvement in research activities. This information has the potential to provide researchers with an acceptable and cost-effective way of contacting cancer patients about research which will further understanding of patient experiences of care.

This project will be the first study examining patient-centred care in outpatient oncology units using a comprehensive scale that documents patients’ perceptions of their experience of care, rather than satisfaction with care. Building on prior research, there is a need to assess the degree to which care is patient-centred in a way that: 1) enables representation of the views of consumers; 2) allows data collection close in time to care provision; and 3) credibly assesses domains of care. The last involves
examining the provision of care, rather than satisfaction with care, across different domains. Criteria for selection of items in each domain of patient-centred care should include whether they are known to: a) be prevalent among cancer patients; b) have a significant impact on cancer patients’ well-being; and c) have the potential to be identified, addressed and monitored by the system.

2.1 Study rationale

What are we asking patients?

The aim of this study is to assess consumer views about a range of issues related to their experiences of cancer and cancer care. Patient-centred care is one of the six objectives for achieving optimal health care, as described by the Institute of Medicine (2001). Patient-centred care a) is responsive to consumer needs, values and preferences, b) integrated and co-ordinated, c) relieves physical discomfort, d) provides emotional support, e) allows for the involvement of family and friends, and f) is supportive of the provision of information, communication and education to enable patients to understand and make informed decisions about their care and manage the effects of their conditions. Patient-centred care is assessed by asking patients to report on their experiences of care, and on their preferences for involvement in treatment, research and advocacy activities.

Why touch screen computers?

Touchscreen computer surveys such as this have the potential to be implemented across a number of cancer clinic settings. Touch screen computer surveys also allow data collection to be linked to a centralised data collection point, eliminating the need for data entry and data checking. Electronic data collection has been associated with less underreporting, fewer inconsistencies and fewer missing values than alternative survey modalities such as paper-and-pencil surveys. Computerised data collection can also provide “real-time” scores, which can be made immediately available to consulting clinicians and patients. There is evidence indicating that touch screen computer surveys are viewed as being a confidential, acceptable, feasible and cost-effective mechanism of collecting information about the psychosocial well-being of cancer patients. Consent rates for completing touch screen self-report assessments in an oncology setting have been found to reach 99.3%. The touch screen computer survey proposed for this study includes branching questions based on
participant responses. This helps to reduce the burden of survey completion, where possible.

2.2 Study aims

To describe and examine:

a) Radiation oncology outpatients’ perceptions of cancer care over the previous three months. Perceived quality of care will be examined for the following domains: cost; clinic waiting times; convenience of appointments; pain; symptoms/side-effects; adherence to medications; information; practical issues; emotional distress; caregiver support; continuity of care; and responsiveness.

b) Radiation oncology outpatients’ perceived experiences of life expectancy discussions.

c) Radiation oncology outpatients’ perceptions of their own psychological distress (compared with results on the Hospital Anxiety and Depression Scale)

d) Whether oncology outpatients’ perceptions of quality of care vary by cancer type, stage of disease, sociodemographic variables or psychological well-being.

To determine:

e) The proportion of breast and colorectal patients who have been asked about family history of cancer

f) The proportion of cancer patients who express interest in being contacted about future research

g) The feasibility and acceptability of a pre-appointment survey.

2.3 Research team

The members of the research team from the University of Newcastle are Professor Rob Sanson-Fisher, Dr. Chris Paul, Professor Catherine D’Este, Dr. Mariko Carey, Miss Amy Anderson, Miss Lisa Mackenzie (PhD Candidate), and Mr Ryan Courtney (PhD Candidate), School of Medicine and Public Health, University of Newcastle.
Site investigators include:

Professor Robyn Ward (Prince of Wales Hospital), Dr Chee Lee (St George and Sutherland Hospitals), Dr William Stevenson (Royal North Shore Hospital), Associate Professor Chris Milross (Royal Prince Alfred Hospital) and Dr Stephen Clarke (Concord Repatriation Hospital).
3. Project materials

a) Recruitment log sheet
This sheet is used to record participant eligibility and consent information. More instructions on how to complete this form are provided in Section 4. A sample of the recruitment log sheet can be seen in Appendix 9.1.1.

b) Patient information statement
This statement provides patients with information regarding the project and how the data collected will be used. A copy of this statement should be given to patients before they begin the study. See Appendix 9.1.2 for a sample.

c) Patient consent form
After patients have completed the touch screen survey, they will be asked for their consent to being contacted for follow-up studies. Those who consent to being contacted will need to complete the patient consent form. This form will ask participants to provide their names, postal addresses, contact numbers and email addresses. See Appendix 9.1.2 for a sample.

d) Touch screen computer survey
This survey will be loaded onto the touch screen computer. Ensure that participants are in a private area of the room before they begin the survey. Survey questions can be seen in Appendix 9.1.3.
4. The recruitment process

1. Ensure that the laptop is turned on and you are logged into the system
   Username: hbrg
   Password: hbrg1

2. From those presenting for an appointment, identify eligible participants (record details regarding eligibility in recruitment log sheet (see Appendix 9.1.1).

   Patients are eligible to participate if they are:
   1. Aged 18 years and above
   2. Able to speak and read English sufficiently
   3. Attending at least their second treatment appointment.

   Reasons for being ineligible include:
   1. Aged below 18 years (Identified by checking medical records)
   2. Unable to provide consent (If the participant is mentally impaired or unable to personally provide consent for themselves)
   3. Unable to read/speak English sufficiently (If the person requires assistance to communicate with reception staff, or when asked about the study indicates that they have difficulty reading or understanding English)
   4. If clinic staff indicate the patient may be too unwell to complete the survey.

3. Note reason for being ineligible on recruitment log sheet [see Appendix 9.1.1]).

4. Explain study procedures to all eligible patients.
   Example script:

   Hi, I am <Your name> from the medical school at The University of Newcastle.
   We are trying to find a way to help improve cancer care. Would you be able
   help us by completing a short survey on a touch screen computer asking about
the care that you have received? Participation in this study will take about 10 minutes. Would you be interested in participating in this project?

5. Provide participants with hard copy information statement (Appendix 9.1.2).

6. Record the unique participant ID and computer number on the recruitment log sheet (see Appendix 9.1.1).

7. Note consent to participate in this study in the recruitment log sheet (see Appendix 9.1.1). Record gender and approximate age group for non-consenters.

8. Once participants are ready to begin survey, ensure they are in a part of a room where they have adequate privacy while completing the survey.

9. Locate the Digivey Launcher icon on Desktop and double click on the icon. Select ‘Project’ from the screen that appears. A list of projects will appear on the screen. Click on ‘A SURVEY OF CANCER CONSUMER VIEWS - JULY’ and the survey will be loaded on the laptop (See Section 6 for more information on moving through the survey). Record whether patients complete the touchscreen survey unassisted, with some assistance, or require full support on the recruitment log sheet (see Appendix 9.1.1).

10. Collect the computer touch screen computer from the participant upon survey completion.

11. For participants who have to exit survey prior to completion, note “Yes” to “interrupted” on the recruitment log sheet (see Appendix 9.1.1). (See Section 6 for more details).

12. After participants have completed the touch screen survey, ask if they are willing to be contacted for future research. If the participants agree, provide them with the patient consent form (Appendix 9.1.2). They will be required to provide their names, phone numbers, postal addresses and email addresses. Participant ID will be printed onto the consent form. Consent forms need to be collected and kept in a safe area.
13. Use alcohol wipes provided to wipe the computer screen before allowing the next participant to use the computer. This is important to minimise the risk of spread of infection.
5. The patient views survey

Your role in administering the survey is to load the questionnaire onto the touch screen computer. You should also ensure that participants understand the patient information sheet (see Appendix 9.1.2) and provide instructions on how to use the touch screen computer. Additionally, you will assist the participants in completing the survey questions by answering any questions they may have.
6. Using the touch screen computer

We will provide you with two touch screen computers and up to three spare batteries for recruitment.

Using the computer

Switch on the laptop and log onto the user, “HBRG”. Insert the password that is provided to you by the program coordinator. Do not disclose this password to non-project-related personnel or practice staff. The battery of the touch screen computer has to be charged for 5 hours prior to use. The battery life of the laptop is approximately 4 hours. The laptop will indicate when the battery is low. The battery icon is located in the notification area on the Windows taskbar. When the charge of the battery is low, a red circle with a white “X” appears above the green battery icon. Please insert a spare battery into the battery slot when the power is low.

Launching the Health Behaviour Questionnaire

When logged into the computer, double click on the green icon called “Digivey Launcher V3” located on the desktop (circled). A Digivey screen will be loaded. Select the “Project” button on the screen.

Image 1: Loading the Digivey survey onto the touch screen computer.
A list of projects will appear. From the list of projects, select “A survey of cancer consumer views - July” and press the “Select” button.

*Image 2:* List of available projects on Digivey Launcher (These may vary between computers).

At the survey start screen, touch the yellow button with the text, “Touch here to begin”.

*Image 3:* Survey start screen.
**Moving through the survey**

The survey will appear as a full screen. The question and instructions will be at the top of the screen. Answer options will be on the lower section of the screen. To select a response, participants need to touch the relevant answer button or enter their response using the key pad or number pad and then touch "NEXT".

The first step involves showing patients how the touchscreen works. Enter the 7-digit unique identification code from the top of the participant’s copy of the information statement. This code is used if the participant needs to exit the survey and then return to complete it later.

![Example: insert participant identification number screen on the touchscreen computer.](image)

**Image 4:** Example: insert participant identification number screen on the touchscreen computer.

The first question in the survey, pictured below should be answered by you (the research assistant). Demonstrate how you use the “NEXT” navigation button to progress through the survey. Once you have shown the participant how the touchscreen works, ask them if they are happy to continue the survey without your assistance.
**Image 5:** Example question screen on the touchscreen computer.

For matrix type questions, participants will need to select an answer from each row, and then press “NEXT”.

**Image 6:** Example of matrix type questionnaire on the touch screen computer.

For questions that require participants to enter or type in information, the number pad or keyboard on the screen can be used to insert answers. To go back, participants can touch the “BACK” button located at the bottom left corner of the screen.
Image 7: Example of number pad question on the touch screen computer.

For ranking questions, participants can skip using the next navigation button, or alternatively rank up to three responses.

Image 8: Example of ranking question on touchscreen computer.

If a participant wishes to exit the survey prior to completion (either to attend the appointment or for other reasons), touch the “EXIT SURVEY” navigation button at the bottom of the screen. After the participant has completed the survey, an end screen will flash for 7 seconds. The “Start screen” will then appear.
To exit from the survey start screen, right click the mouse. A cursor will appear. Right click on the TOP RIGHT side of the screen to exit. This will only work when the survey is at the “Start Screen” (see Image 3). Alternatively, press the CTRL, ALT and DEL keys on the keyboard. Select “Start Task Manager” from the list and “End Task for Digivey Launcher”.

Image 9: Example of resuming an interrupted survey using unique participant identification code.

To resume an interrupted survey, you will need to re-launch the Digivey program by selecting “A survey of cancer consumer views - July” and pressing the “Select” button. Select the appropriate identification number and touch the “RESUME NOW” button.

Remember to wipe down the touch screen computer with alcohol wipes before handing the touch screen computer to the next participant.

Downloading data

To download data onto an external USB drive, insert a USB flash drive into the laptop. Create a folder entitled “Digivey projects”. Double click the “Digivey Launcher V3” icon located on the desktop. Select Data transfer. Click on the “Select target drive” button and browse to locate your USB flash drive folder. After you have located the folder, press “Save”. Please ensure the “No Action, Keep Records” option is selected. After
you have done this, press the “Transfer Results” button. All new records will be saved into your flash drive.

7. Frequently asked questions (FAQS)

This section addresses potential questions that participants may have regarding this research project and the possible answers to the questions.

Why should I participate in this research project?

We are trying to get views from as many cancer patients as possible about areas of cancer care that could be improved. Even if you don't think anything could be improved, we are still very interested in hearing your views about cancer care.

How will the researchers use the information collected?

The information collected will be published in scientific journals. Any information that may identify you personally, such as your name and location or those of anyone else you mention, will be removed or changed. If you have further concerns regarding the use of the information you provide, the name and contact details of the researcher is provided on the patient information sheet.

How do I use the touch screen computer?

I will start up the survey on the touch screen computer. You need to read each question and select the appropriate answer by touching it with your finger. The next question will then appear on the screen. If you are called in for your appointment while completing the survey, please return the computer to me and I will exit the survey for you.

What should I do if I’m called in to my appointment but I have not completed the questions?

If you are called in for your appointment, you will be able to exit the questionnaire. It is up to you whether you would like to come back and complete the survey after your appointment. If you do come back, we can log you back into the survey where you finished up before your appointment, using your unique identification code.
Why do the researchers want information regarding my family’s medical history?

Your family history may increase your risk for certain types of disease. This information is helpful in determining what sort of screening tests may be relevant for you.

Will my information be kept private?

If you choose to complete the surveys, your privacy will be protected. Individual participants will not be identified in any of the reports arising from the information. Data will only be presented in summarised form. Your data would be stored securely using an identification number, not your name, and only the research team would have access.

In situations where participants ask for medical advice regarding health conditions, please refer participants to speak to their healthcare provider (e.g. general Practitioner or cancer doctor).

DO NOT ATTEMPT TO PROVIDE ANY MEDICAL ADVICE TO PARTICIPANTS.
8. COMMUNICATION ISSUES

a) Communication with the participants

What to do when a participant becomes upset or distressed?

If a participant becomes upset, ask them if they would like to stop the survey. Reassure them that it is OK to change their mind about participation. Encourage the participant to talk to their doctor about what has upset them. Ensure that the participant has a copy of the information sheet and knows who they can contact if they have concerns about the research.

What to do when I am unable to answer a patient’s question?

Call Dr. Mariko Carey or Miss Lisa Mackenzie and ask if they can assist with the patient enquiry. If the request is not urgent, leave a message and ask for one of the researchers to call you back.

(b) Communication with the research team

How do I download data from the computer?

The research team will provide you with an external hard drive. To download data, insert a USB flash drive into the laptop. Create a folder entitled “Digivey projects”. Double click on the “Digivey Launcher V3” icon located on the desktop. Select “Data transfer” and select your USB flash drive folder as the target drive. Press “Transfer results” and select “GP project’” All new records will be saved onto your flash drive.

Who can I send data to?

Data can be sent to Dr Mariko Carey at Mariko.Carey@newcastle.edu.au.

Important: Please remember to follow the above instructions as this will enable encryption of data and protection of patient privacy. After you have sent the data, please call Dr Mariko Carey at 02 49138320 to inform her of the password.
9. Maintaining the touch screen computer

Charging batteries

If you are responsible for bringing the touchscreen computers to the clinic, please ensure the batteries (including spare batteries) are fully charged. This will ensure you can make the most out of your time in the clinic.

Error messages

*Image 10: Example: error message*

On occasion we have had issues with error messages appearing whilst patients are completing the survey. If an error message appears you will need to take note of which screen the message occurred on. Touch “OK”, and then restart the survey using the participants’ unique ID code. Explain to the participant that their answers up to that point are saved, but you will need to manually get them up to the same point in the survey by entering dummy data. Once the survey is completed, you will need to create a folder on the external hard drive with the participant ID number, and save the “DIGIVEY SAFETY COPY” accessible from C:/DigiveySafetyCopy.

Trouble shooting process
What to do when there is a breakdown/malfunction of the touch screen computer tool?

Please refer to the DELL computer manual provided with each touch screen computer. If the problem cannot be solved after referring to the manual, please contact the research team at the University of Newcastle.

If you have any general or project-related questions, please contact:

**Dr. Mariko Carey**

Contact no: 02 49138320

**Miss Serene Yoong**

Contact no: 02 49138945

**Miss Lisa Mackenzie**

Contact no: 02 4913 8682
10. References


17. Allenby A, Matthews J, Beresford J, McLachlan SA. The application of computer touch-screen technology in screening for psychosocial distress in an
## Appendix 9.1.1: Example study log sheet

### Hospital Recruitment Log Sheet

<table>
<thead>
<tr>
<th>DATE:</th>
<th>HOSPITAL:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RA Name: ____________________________________________

<table>
<thead>
<tr>
<th>Exclusions</th>
<th>Consent ?</th>
<th>If yes, ID#</th>
<th>Com p #</th>
<th>Sex</th>
<th>Approx age group</th>
<th>Survey status (circle)</th>
<th>Completion mode (circle)</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>#</td>
<td>1st visit</td>
<td>Non-English-speaking</td>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1st visit</td>
<td>No</td>
<td>Yes</td>
<td>M F</td>
<td>25-34 45-54 &gt;6 5</td>
<td>Complete</td>
<td>Interrupt</td>
<td>Some assistance</td>
</tr>
<tr>
<td>2</td>
<td>1st visit</td>
<td>No</td>
<td>Yes</td>
<td>M F</td>
<td>25-34 45-54 &gt;6 5</td>
<td>Complete</td>
<td>Interrupt</td>
<td>Some assistance</td>
</tr>
<tr>
<td>3</td>
<td>1st visit</td>
<td>No</td>
<td>Yes</td>
<td>M F</td>
<td>25-34 45-54 &gt;6 5</td>
<td>Complete</td>
<td>Interrupt</td>
<td>Some assistance</td>
</tr>
<tr>
<td>4</td>
<td>1st visit</td>
<td>No</td>
<td>Yes</td>
<td>M F</td>
<td>25-34 45-54 &gt;6 5</td>
<td>Complete</td>
<td>Interrupt</td>
<td>Some assistance</td>
</tr>
<tr>
<td>5</td>
<td>1st visit</td>
<td>No</td>
<td>Yes</td>
<td>M F</td>
<td>25-34 45-54 &gt;6 5</td>
<td>Complete</td>
<td>Interrupt</td>
<td>Some assistance</td>
</tr>
</tbody>
</table>

### DAILY TOTALS:

- Total approached: ____________________________
- Total ineligible: ____________________________
- Total refused: ____________________________
- Total consented: ____________________________
- Total completed: ____________________________
Appendix 9.1.2: Example information statement and consent form
PARTICIPANT INFORMATION STATEMENT:
Assessing patient views on the quality of cancer care

The Research Team
Professor Rob Sanson-Fisher
Dr Mariko Carey
Dr Christine Paul
Miss Lisa Mackenzie
Mr Ryan Courtney
Professor Robyn Ward
Professor Catherine D’Este

Invitation
You are invited to participate in a research study. This study will ask about cancer patients’ views on the quality of cancer care.

The study is being conducted by Professor Rob Sanson-Fisher, Dr Mariko Carey and Dr Christine Paul from the University of Newcastle, and Professor Robyn Ward from the Prince of Wales Hospital. The research is part of Lisa Mackenzie’s and Ryan Courtney’s PhD studies at the University of Newcastle. Lisa is supervised by Rob Sanson-Fisher, Mariko Carey and Catherine D’Este from the School of Medicine and Public Health. Ryan is supervised by Professor Rob Sanson-Fisher, Dr Christine Paul and Professor Catherine D’Este from the School of Medicine and Public Health.
Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Feel free to discuss it with others, if you wish.

If you agree to participate in this study, you will be asked to complete a touch screen computer survey. The survey will ask you questions about yourself, your cancer and your cancer treatment. You may also be asked about the quality of the care you have been receiving at this clinic, how you are coping, helping others with cancer, and how acceptable you find this survey. Each participant will only answer questions about some of the above topics so that the survey is kept as short as possible. You will also be asked whether you are willing to be contacted by researchers about future studies.

1. What is the purpose of this study?

The purpose of this study is to look at the views that cancer patients have about the quality of their cancer care. This information will help to find areas where patients think that care could be improved. The study will also help us to see if there are differences in views about quality of cancer care between different groups of cancer patients (e.g. patients with different cancer types).

2. Why have I been invited to participate in this study?

We are seeking people aged over 18 years and diagnosed with cancer, who are attending an outpatient appointment to receive cancer care at <Insert Hospital Name>. People who have attended the clinic at least once before, are English-speaking, and have not completed the survey before will be invited to participate.

3. What if I don’t want to take part in this study, or if I want to withdraw later?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

If you do decide to participate, you may withdraw from the project at any time up to completion of the survey. You do not need to give a reason for withdrawing. If you choose to provide your name and contact details (see section below on “What does this study involve?”) it will be possible for you to withdraw your data after the survey is completed. If your name and contact details are not provided, your data will not be identifiable. Therefore, your data cannot be withdrawn.

4. What does this study involve?

This study will be conducted over a period of approximately two months. It will be conducted with patients receiving cancer care at the following hospitals: Prince of Wales Hospital, St George Hospital, Sutherland Hospital, Royal North Shore Hospital, Royal Prince Alfred Hospital and Concord Repatriation General Hospital.
If you agree to participate in this study, you will then be asked to complete a survey by touch screen computer. You will be asked to do this while waiting for your appointment with your cancer doctor. It is expected that the survey will take 13 to 20 minutes to complete. The touch screen computer will be set up to ensure your privacy while completing the survey. Where possible, a private consulting room will be used. If your doctor is ready to see you while you are completing your survey, you can choose to exit the survey and resume it later, if you would like to.

We would also like to ask if you are willing to be contacted in the future about other research studies. If you are willing to be contacted, you will also be asked to provide your name and contact details. You are not being asked to consent to participate in other studies at this stage. You are only being asked to give permission for the researchers to contact you again. If you indicate that you are not willing to be contacted again, your survey results from today will be completely anonymous. If you indicate that you are willing to be contacted, your survey results from today will be separated from your contact details. These will be linked only by an identification code.

5. How is this study being paid for?

This study is being supported by the PhD research support money of Miss Lisa Mackenzie and Mr Ryan Courtney. The researchers have no commercial interest in the outcome of this study.

6. Are there risks to me in taking part in this study?

It is not expected that you will be exposed to any risks by participating in this study. There may be some inconvenience due to the time taken to complete the survey. It is not expected that completing the survey will cause any distress. However, if participation does raise any questions or concerns about your cancer, we encourage you to discuss these with your doctor or contact the Cancer Helpline on 131120 (Monday-Friday, 9am-5pm).

7. Will I benefit from the study?

This study aims to increase understanding of patients’ experiences of cancer. The study may improve the quality of cancer care for future patients. However, it will not directly benefit you.

8. Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. You will not be paid any fees for participating in this research.

9. How will my confidentiality be protected?

If you decide not to provide your contact details, your survey results from today will be anonymous. It will not be possible to identify you from your answers. If you choose to provide your contact details, this information will be stored separately from your survey
responses. Your information will be linked by an identification code. Information about you that is collected during this study will remain confidential. It will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results. These will be held securely at The University of Newcastle.

All electronic data will be stored on a secure server at The University of Newcastle. We will use password protection to keep your data private. Data will be retained for at least 5 years at The University of Newcastle. This will allow the completion of the research project. Once the project has been finalised, we will delete the electronic data files.

You may choose to provide your contact details when completing the survey. This will indicate your willingness to be contacted again about future research. If so, only the research team listed above will contact you to invite you to participate in these future studies. Your contact details will be stored for up to 5 years on a secure server at The University of Newcastle. We will use password protection to keep your contact details private. If you are contacted, you can choose whether or not to participate in any further studies. Ethics approval will be sought for any further studies.

10. What happens with the results?

We plan to discuss the results of this study with staff at the Prince of Wales Hospital, St George Hospital, Sutherland Hospital, Royal North Shore Hospital, Royal Prince Alfred Hospital and Concord Repatriation General Hospital. We also plan to publish results in peer-reviewed journals, and at conference presentations or other professional forums. Results will also be presented in theses submitted as part of Lisa Mackenzie’s and Ryan Courtney’s PhD studies. The information in these publications will be presented in such a way that you cannot be identified. If you wish to receive the study results you should contact Professor Rob Sanson-Fisher (contact details listed above).

11. What should I do if I want to discuss this study further before I decide?

Please read this Information Statement. Be sure you understand its contents before you consent to participate. The researcher will discuss the research with you. The researcher will answer your questions and explain anything you do not understand. If you would like to know more at any stage, please do not hesitate to contact Professor Rob Sanson-Fisher on (02) 4913 8169 or Rob.Sanson-Fisher@newcastle.edu.au.

If you would like to participate, please complete the touch screen computer survey whilst waiting for your appointment. This will be taken as your informed consent to participate. If you are willing to provide your contact details, please select “Yes” on the attached consent form. If you provide your contact details you are indicating that you are willing to be contacted about future research. If you are contacted, you can choose whether or not to participate in these further studies.

12. Who should I contact if I have concerns or complaints about the conduct of this study?

This project has been approved by the University’s Human Research Ethics Committee, Approval No. H-2009-0283, and the NSW Population and Health Services
Research Ethics Committee at the Cancer Institute NSW, Approval No. 2009/12/209. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au. Alternatively, you may contact the Ethics Coordinator at the Cancer Institute of NSW on (02) 8374 5615 or via email: ethics@cancerinstitute.org.au.

Thank you for taking the time to consider this study.

If you wish to take part in it, please complete the touch screen computer survey.

This information sheet is for you to keep.

Rob Sanson-Fisher
Professor of Health Behaviour
The University of Newcastle

Lisa Mackenzie
PhD Candidate
The University of Newcastle

Ryan Courtney
PhD Candidate
The University of Newcastle
Consent Form for the Research Project:

Assessing patient views on the quality of cancer care

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

If you wish to participate in this study please complete the touchscreen computer survey while waiting for your appointment today. This will be taken as your consent to participate.

We would also like to ask if you are willing to be contacted in the future about other research studies.

Do you consent to being contacted (by mail, e-mail or telephone) about future research?

Please circle your response:  

YES  /  NO

If you consent, you may be contacted within the next 12 months and invited to take part in surveys that assess the opinions and experiences of people who have cancer. The information provided in the surveys will be used to help improve cancer services. If you agree to be contacted, you can still choose whether or not to participate in the study at that time.

If YES, up to how many surveys would you be willing to be contacted about each year?_____

I understand that my personal information will remain confidential to the researchers, except as required by law.

I have had the opportunity to have questions answered to my satisfaction.
Name: ....................................................................................................................

Postal address: ........................................................................................................
........................................................................................................
........................................................................................................

Phone number: ......................................................................................................

E-mail address: ......................................................................................................

Signature: _______________________________ Date: ________________
Appendix 9.1.3: Survey with information screenshots
A SURVEY OF CANCER CONSUMER VIEWS (English text)

**Question Name = ID number**
Enter 7 digit ID number and then touch "NEXT".

Please insert participant identification number.

**Question Name = Hospital**
Please touch your response and then touch the "NEXT" button to continue.

Which hospital are you attending today?
   - Prince of Wales
   - St George
   - Sutherland
   - Royal Prince Alfred
   - Concord
   - Royal North Shore
Question Name = Introduction screen

Your views are important to us.

Please touch the "NEXT" button on the screen when you are ready to start the survey.

We are very interested in your views about the cancer care that you have received. The information you give us will help us to identify how cancer care might be improved in the future. The study will also help us to see if there are differences in views about quality of cancer care between different groups of people (e.g. patients with different cancer types).

All information that you give will remain confidential. Your answers may help us to identify areas where care may be improved.

Question Name = Gender

Please touch your response and then touch the "NEXT" button to continue.

Are you male or female?

Male
Female

Question Name = Year of birth

Please enter your response and then touch the "NEXT" button to continue.

In which year were you born?

Question Name = Month of birth

Please touch your response and then touch the "NEXT" button to continue.

In which month were you born?

January
February
March
April
May
June
July
August
September
October
November
December

Question Name = Date of birth

Please enter your response and then touch the "NEXT" button to continue.

On which date in <Month of birth> <Year of birth> were you born?
**Question Name = Postcode**
Enter your postcode. If you do not know your postcode, please touch "NEXT" to continue.

Please enter the postcode of your usual place of residence.

**Question Name = Area**
Please enter your response and then touch "NEXT" to continue.

What is the name of your suburb/town?

**Question Name = Type of cancer**
If you have had more than one type, CHOOSE ONLY THE MOST RECENT PRIMARY CANCER. Then touch "NEXT".

What type of cancer do you have?
- Brain
- Breast
- Colorectal (bowel)
- Head and neck
- Lung
- Melanoma
- Non-Hodgkin's Lymphoma
- Prostate
- I don't know my diagnosis
- Other cancer

**Question Name = Other 010**
If you have had more than one type, CHOOSE ONLY THE MOST RECENT PRIMARY CANCER. Then touch "NEXT".

Please indicate what type of cancer you have:
- Bladder
- Cervical
- Kidney
- Leukaemia
- Lip
- Liver
- Oesophageal
- Mesothelioma
- Ovarian
- Pancreatic
- Testicular
- Thyroid
- Uterus
- Other

**Question Name = Other 012**
Please insert your answer using the keyboard on screen.

Please specify the type of cancer you have.
**Question Name = First diagnosed with cancer - year**
Please enter your response and then touch "NEXT".

In what year were you diagnosed with this cancer?

**Question Name = First diagnosed with cancer - month**
Please touch your response. If you are unsure, please make your best guess. Then touch "NEXT".

In what month of <First diagnosed with cancer - year> were you diagnosed with this cancer?
- January
- February
- March
- April
- May
- June
- July
- August
- September
- October
- November
- December

**Question Name = Second diagnosis**
Please touch your response and then touch "NEXT".

Have you ever had a second diagnosis or recurrence?
- Yes, second cancer diagnosis (a completely new type of cancer, unrelated to the first cancer)
- Yes, cancer recurrence (the same cancer returning after a period of remission, either to where it originated or to a different part of the body)
- Not sure
- No

**Question Name = Treatment stage**
Please touch your response and then touch "NEXT".

Please select the option which best describes where you are up to with your treatment.
- Recently diagnosed, not yet started treatment
- Having check-ups
- Receiving treatment (e.g. chemotherapy, radiation therapy, surgery, stem cell/bone marrow transplant)

**Question Name = treatment aim**
Please touch your response and then touch "NEXT".

What do you understand to be the main aim of your current cancer treatment?
- To cure the cancer
- To prevent the cancer from coming back
- To control symptoms of cancer (cure is not possible)
**Question Name = Type of health insurance**
Please touch your response and then touch "NEXT".

What type of private health insurance do you have?
- Hospital cover only
- Extras cover only
- Hospitals and Extras cover
- Not sure
- I do not have private health insurance

**Question Name = Country of birth**
Please touch your response and then touch "NEXT".

Were you born in Australia?
- Yes
- No

**Question Name = Other 019**
Please touch your response and then touch "NEXT".

What is your country of birth?
- United Kingdom and Ireland
- China
- New Zealand
- Vietnam
- Philippines
- India
- Lebanon
- Italy
- Hong Kong
- Greece
- Korea
- South Africa
- Malaysia
- Other

**Question Name = Other country**
Please insert your answer using the keyboard on screen.
Please specify your country of birth.

**Question Name = ATSI status**
Please select all that apply, and then touch "NEXT".

Are you of Aboriginal or Torres Strait Islander background?
- Yes, Aboriginal
- Yes, Torres Strait Islander
- No

**Question Name = Living**
Please select all that apply, and then touch "NEXT".

Who lives with you?
- My husband/wife/partner
- My child/children and/or stepchild/children
Other family
   A friend or friends
   An unrelated flat mate or co-tenant
   I live alone

**Question Name = Outpatient appointments at this clinic**
Please touch your response and then touch "NEXT".

On how many separate occasions IN THE LAST 3 MONTHS have you attended an outpatient appointment AT THIS CLINIC?
0
1
2
3
4
5
6
7
8
9
10
More than 10

**Question Name = Outpatient appointments at this clinic - other**
Please enter your response and then touch "NEXT".

Please specify how many outpatient appointments you have attended AT THIS CLINIC IN THE LAST 3 MONTHS.

**Question Name = Number of times seen cancer doctor**
Please touch your response and then touch "NEXT".

On how many separate occasions IN THE LAST 3 MONTHS have you had an appointment with your cancer doctor(s) at this hospital?
0
1
2
3
4
5
6
7
8
9
10
More than 10

**Question Name = Number of times seen cancer doctor - calculator**
Please enter your response and then touch "NEXT".

Please specify how many appointments you have had with your cancer doctor(s) at this hospital IN THE LAST 3 MONTHS.
Cancer patients have indicated that improvements in some areas of care may improve their well-being. The next section asks you to indicate if your well-being would have been improved with different care.

Your answers are strictly confidential. Your answers may help us to identify areas where care may be improved.

Question Name = Quality of care - physical symptoms

During my cancer care, my well-being would have been greatly improved by:
BETTER MANAGEMENT OF MY PHYSICAL SYMPTOMS.

Please touch your level of agreement with this and then touch "NEXT".

Question Name = Quality of care - Information and communication

During my cancer care, my well-being would have been greatly improved by:
BETTER INFORMATION AND COMMUNICATION ABOUT MY CANCER AND CARE.

Please touch your level of agreement with this and then touch "NEXT".
Question Name = Quality of care - emotional and spiritual support

During my cancer care, my well-being would have been greatly improved by:

BEetter EMOTIONal AND/or SPIRITuAL suPPORT.

Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree  Disagree  Agree  Strongly agree

EMOTIONAL AND OR SPIRITUAL SUPPORT may include services or support to help you cope with the impact of cancer on your life, doubts/worries, feelings of anxiety or sadness, changes to your body image etc.

Question Name = Quality of care - services, information and support for family

During my cancer care, my well-being would have been greatly improved by:

BEetter SERVICEs, INFORMATION AND SUPPORT FOR MY FRIENDS/FAMILY.

Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree  Disagree  Agree  Strongly agree

SERVICES, INFORMATION AND SUPPORT FOR YOUR FRIENDS/FAMILY may include helping them to cope with the impact of your cancer, or providing opportunities for them to be involved in your care.

Question Name = Quality of care - staff approachability and respect for me

During my cancer care, my well-being would have been greatly improved by:

BEetter STAFF APPROACHABILITY AND RESPECT FOR ME.

Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree  Disagree  Agree  Strongly agree

STAFF APPROACHABILITY AND RESPECT FOR ME describes staff who are easy to contact and up-to-date with your medical history, and who give you opportunities to ask questions and be involved in treatment decisions.
Question Name = Quality of care - getting access to the care I need when required

During my cancer care, my well-being would have been greatly improved by:
GETTING BETTER ACCESS TO THE CARE I NEED WHEN REQUIRED.
Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree | Disagree | Agree | Strongly agree

GETTING ACCESS TO THE CARE I NEED WHEN REQUIRED describes:
- not having to wait too long to get appointments,
- and having treatment and medical advice available when needed.

BACK | EXIT SURVEY

Question Name = Quality of care - services and support to cope with changes to my relationships

During my cancer care, my well-being would have been greatly improved by:
BETTER SERVICES/SUPPORT TO COPE WITH CHANGES TO MY RELATIONSHIPS.
Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree | Disagree | Agree | Strongly agree

SERVICES/SUPPORT TO COPE WITH CHANGES TO YOUR RELATIONSHIPS may include:
- knowing what changes to expect, and having some strategies to reduce the impact of cancer on your work, usual social activities, friendships or sexual relationships.

BACK | EXIT SURVEY

Question Name = Quality of care - services or advice to assist with practical concerns

During my cancer care, my wellbeing would have been greatly improved by:
BETTER SERVICES/ADVICE TO ASSIST ME WITH PRACTICAL CONCERNS.
Please touch your level of agreement with this and then touch "NEXT".

Strongly disagree | Disagree | Agree | Strongly agree

SERVICES/ADVICE TO ASSIST YOU WITH PRACTICAL CONCERNS may include:
- being able to access financial support, transport to treatment, home help services or other support needed to manage practical issues.

BACK | EXIT SURVEY
Question Name = Quality of care - improvement ranking

Please rank up to 3 aspects of cancer care that would have helped you the most if they were improved:
In order, touch the 1st, 2nd and then 3rd most important areas for improvement.

- Management of my physical symptoms (e.g. pain, side effects or symptoms)
- Services/advice to assist me with practical concerns (transport, home help etc.)
- Information and communication about my cancer and care
- Services/support to cope with relationship changes
- Staff approachability and respect for me
- Emotional and/or spiritual support
- Getting access to the care I need when required
- Services, information and support for my friends/family

Question Name = Willingness to complete section

Please indicate whether or not you are willing to complete these questions by touching your response.
The following questions ask for your views about your life expectancy.
This will provide information that may help to improve services for cancer patients.
I am willing to complete this section of the survey
Please skip to the next section of the survey

Question Name = Life expectancy discussion preferences

Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".
When discussing life expectancy, I would prefer my doctor to:
- Ask me if I want to discuss life expectancy
- Just tell me what they think I can cope with
- Just tell me the good news
- Tell me everything they can
- Tell my partner or family and let them decide whether I should be told
STRONGLY DISAGREE
DISAGREE
AGREE
STRONGLY AGREE

Question Name = Life expectancy discussion

Please touch your response and then touch "NEXT".

Have you and your cancer doctor talked about your life expectancy?
Yes
No

Question Name = Life expectancy discussion initiation

Please touch your response and then touch "NEXT".

How did the discussion about life expectancy begin?
- I asked my doctor if we could talk about it
- My doctor asked me if I wanted to talk about it
- My doctor discussed it without asking me first
Other

**Question Name = Life expectancy - which cancer doctor**
Please touch all responses that apply to you and then touch "NEXT".

Which doctor/s have you discussed your life expectancy with?
- Surgeon
- Medical Oncologist
- Radiation Oncologist
- Haematologist
- Other cancer specialist/s

**Question Name = Life expectancy estimate**
Please touch your response and then touch "NEXT".

While my cancer doctor cannot be certain, he/she has told me that it is probable that:
- My cancer diagnosis will not affect my life expectancy
- I will live more than 5 years
- I will live for 2-5 years
- I will live for less than 2 years

**Question Name = Life expectancy - agreement with estimates**
Please touch your response and then touch "NEXT".

Do you agree with the life expectancy estimate that your cancer doctor gave you?
- No, I think I will live longer than my doctor suggested
- No, I don't think I will live as long as my doctor suggested
- Yes, I think I will live as long as my doctor suggested
- In my circumstances, no-one really knows

**Question Name = Life expectancy discussion outcomes**
Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".

The information my cancer doctor gave me on life expectancy:
- Was easy to understand
- Was discussed sensitively
- Helped me to plan for the future
- Gave me some degree of certainty
- Made me anxious
- Overloaded me with information
  - STRONGLY DISAGREE
  - DISAGREE
  - AGREE
  - STRONGLY AGREE

**Question Name = Life expectancy - do you want to discuss**
Please touch your response and then touch "NEXT".

Would you like to talk to your cancer doctor about your life expectancy?
- Yes
- No
Question Name = Life expectancy - why not discussed yet
Please touch your response and then touch "NEXT".

Why haven't you discussed life expectancy with your cancer doctor?
  Waiting for my doctor to start the discussion
  My doctor is too busy
  My doctor seems uncomfortable with the discussion
  I would feel uncomfortable discussing my life expectancy
  I would rather focus on more immediate concerns (e.g. pain)
  Other

Question Name = Life expectancy - any health professionals
Please touch all responses that apply to you and then touch "NEXT".

Have you talked to any other health professionals about how cancer might influence your life expectancy?
  Yes, Radiation Therapist
  Yes, Nurse
  Yes, GP
  Yes, other health care professional
  No, have not discussed my life expectancy with any other health professional

Question Name = Life expectancy - hindsight preferences
Please touch your response and then touch "NEXT".

Given what you know now, how do you feel about being given life expectancy information?
  I wish I hadn't been told my life expectancy
  I am glad I was told about my life expectancy

Question Name = HADS Info
Hospital Anxiety and Depression Scale (HADS)
Please read the text below and then touch "NEXT" to continue.

Read each item on the following screen. For each item, touch the screen to indicate the reply which comes closest to how you have been feeling in the past week.
Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought out response.

Record data may be published in any scientific journal with acknowledgement.

Back EXIT SURVEY NEXT
**Question Name = HADS1**
Please select the option that most closely describes how you have been feeling in the past week.
I feel tense or 'wound up'.
  - Most of the time
  - A lot of the time
  - From time to time, occasionally
  - Not at all

**Question Name = HADS2**
Please select the option that most closely describes how you have been feeling in the past week.
I still enjoy the things I used to enjoy.
  - Definitely as much
  - Not quite so much
  - Only a little
  - Hardly at all

**Question Name = HADS3**
Please select the option that most closely describes how you have been feeling in the past week.
I get a sort of frightened feeling as if something awful is about to happen.
  - Very definitely and quite badly
  - Yes, but not too badly
  - A little, but it doesn't worry me
  - Not at all

**Question Name = HADS4**
Please select the option that most closely describes how you have been feeling in the past week.
I can laugh and see the funny side of things
  - As much as I always could
  - Not quite so much now
  - Definitely not so much now
  - Not at all

**Question Name = HADS5**
Please select the option that most closely describes how you have been feeling in the past week.
Worrying thoughts go through my mind.
  - A great deal of the time
  - A lot of the time
  - From time to time but not too often
  - Only occasionally

**Question Name = HADS6**
Please select the option that most closely describes how you have been feeling in the past week.
I feel cheerful.
  - Never
  - Not often
  - Sometimes
  - Most of the time
**Question Name = HADS7**
Please select the option that most closely describes how you have been feeling in the past week.
I can sit at ease and feel relaxed.
  - Definitely
  - Usually
  - Not often
  - Not at all

**Question Name = HADS8**
Please touch your response.
I feel as if I am slowed down.
  - Nearly all the time
  - Very often
  - Sometimes
  - Not at all

**Question Name = HADS9**
Please select the option that most closely describes how you have been feeling in the past week.
I get a sort of frightened feeling like "butterflies" in the stomach.
  - Not at all
  - Occasionally
  - Quite often
  - Very often

**Question Name = HADS10**
Please select the option that most closely describes how you have been feeling in the past week.
I have lost interest in my appearance.
  - Definitely
  - I don’t take as much care as I should
  - I may not take quite as much care
  - I take just as much care as ever

**Question Name = HADS11**
Please select the option that most closely describes how you have been feeling in the past week.
I feel restless as if I have to be on the move.
  - Very much indeed
  - Quite a lot
  - Not very much
  - Not at all

**Question Name = HADS12**
Please select the option that most closely describes how you have been feeling in the past week.
I look forward with enjoyment to things.
  - As much as I ever did
  - Rather less than I used to
  - Definitely less than I used to
  - Hardly at all
**Question Name = HADS13**
Please select the option that most closely describes how you have been feeling in the past week.
I get sudden feelings of panic.
- Very often indeed
- Quite often
- Not very often
- Not at all

**Question Name = HADS14**
Please select the option that most closely describes how you have been feeling in the past week.
I can enjoy a good book or radio or TV programme.
- Often
- Sometimes
- Not often
- Very seldom

**Question Name = A and D - Treatment preferences**
Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".

IF YOU WERE experiencing ANXIETY OR DEPRESSION, would you accept the following types of professional help?
- Group counselling AT THE CANCER CENTRE
- Individual counselling AT THE CANCER CENTRE
- Treatment/counselling FROM MY CANCER DOCTOR
- Group counselling OUTSIDE THE CANCER CENTRE
- Individual counselling OUTSIDE THE CANCER CENTRE
- Treatment/counselling FROM MY GP
- Internet (online) support
- NO, DEFINITELY NOT
- NO, PROBABLY NOT
- YES, PROBABLY
- YES, CURRENTLY USING

**Question Name = ANXIETY - Self rated anxiety**
Please select the option that most closely describes how you have been feeling in the past week.
What level of ANXIETY have you been experiencing IN THE LAST WEEK?
- No anxiety
- Mild anxiety
- Moderate Anxiety
- Severe Anxiety

**Question Name = DEPRESSION - Self rated depression**
Please select the option that most closely describes how you have been feeling in the past week.
What level of DEPRESSION have you been experiencing IN THE LAST WEEK?
- No depression
- Mild depression
- Moderate depression
- Severe depression
Given your current levels of ANXIETY AND/OR DEPRESSION, would you like to be offered some professional help?
Yes
No

Why don't you want professional support for ANXIETY and/or DEPRESSION?
Not experiencing much anxiety/depression
Anxiety/depression is normal for someone in my situation
My anxiety/depression is not much higher than usual
Don't think professional assistance would help
My anxiety/depression will reduce once this phase of treatment is over

Now we would like to ask you some questions about this survey. Your answers to these questions will help us to improve the survey for future use.

When completing the survey today:
The instructions were easy to follow
The questions were easy to understand
The touch screen was easy to use
I had enough time to complete all the questions
I felt comfortable answering the questions
The touchscreen allowed enough privacy
STRAONGLY DISAGREE
DISAGREE
AGREE
STRAONGLY AGREE
How often would you be willing to complete this survey (with different questions each time) while waiting to see your oncologist?

- Only once (just this survey)
- Less than half the visits
- Half of the visits
- Most visits
- Every visit

Thank you for the time you have given to complete this survey. Your responses will help us to identify how care might be improved for people with cancer in the future.

Please touch “NEXT” and return the touchscreen computer to the researcher.
Appendix 9.2: Example of touch screen computer survey skip logic
001 - ID number
Question Text: Please insert participant identification number.
Question Header: Enter 7 digit ID number and then touch "NEXT".
Question Type: Open Ended, Verbatim Text
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

002 - Hospital
Question Text: Which hospital are you attending today?
Question Header: Please touch your response and then touch the "NEXT" button to continue.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

003 - Intro screen
Question Text: Your views are important to us.
Question Header: Please touch the "NEXT" button on the screen when you are ready to start the survey.
Question Type: Information Screen
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

004 - Gender
Question Text: Are you male or female?
Question Header: Please touch your response and then touch the "NEXT" button to continue.
Question Type: Closed Ended, Single Choice
005 - Year of birth
Question Text: In which year were you born?
Question Header: Please enter your response and then touch the "NEXT" button to continue.
Question Type: Open Ended, Numeric

006 - Month of birth
Question Text: In which month were you born?
Question Header: Please touch your response and then touch the "NEXT" button to continue.
Question Type: Closed Ended, Single Choice

007 - Date of birth
Question Text: On which date in <Month of birth> <Year of birth> were you born?
Question Header: Please enter your response and then touch the "NEXT" button to continue.
Question Type: Open Ended, Numeric

008 - Postcode
Question Text: Please enter the postcode of your usual place of residence.
Question Header: Enter your postcode. If you do not know your postcode, please touch "NEXT" to continue.
Question Type: Open Ended, Numeric
This question does NOT belong to a Randomizer Group and is NOT hidden.

Skip Conditions: This question is not subject to any skip condition

Branch Condition: The survey will continue with the next question in sequence

009 - Area

Question Text: What is the name of your suburb/town?

Question Header: Please enter your response and then touch "NEXT" to continue.

Question Type: Open Ended, Verbatim Text

This question does NOT belong to a Randomizer Group and is NOT hidden.

Skip Conditions: This question will not be skipped if the following conditions are met:

If Question '008 - Postcode' as a whole question is not answered

Branch Condition: The survey will continue with the next question in sequence

010 - Type of cancer

Question Text: What type of cancer do you have?

Question Header: If you have had more than one type, CHOOSE ONLY THE MOST RECENT PRIMARY CANCER. Then touch "NEXT".

Question Type: Closed Ended, Single Choice

This question does NOT belong to a Randomizer Group and is NOT hidden.

Skip Conditions: This question is not subject to any skip condition

Branch Condition: The following choices cause the survey to continue with other than the next question in sequence:

Button: “09 - I don't know my diagnosis” causes the survey to continue with Question: “013 First diagnosed with cancer – year”

011 - Other 010

Question Text: Please indicate what type of cancer you have:

Question Header: If you have had more than one type, CHOOSE ONLY THE MOST RECENT PRIMARY CANCER. Then touch "NEXT".

Question Type: Closed Ended, Single Choice

This question does NOT belong to a Randomizer Group and is NOT hidden.

Skip Conditions: This question will not be skipped if the following conditions are met:

If Question “010 - Type of cancer” Button: “10 - Other cancer” is selected

Branch Condition: All answer choices cause the survey to continue with the next question in sequence
012 - Other 012
Question Text: Please specify the type of cancer you have.
Question Header: Please insert your answer using the keyboard on screen.
Question Type: Open Ended, Verbatim Text
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “011 - Other 010” Button: “14 – Other” is selected
Branch Condition: The survey will continue with the next question in sequence

013 - First diagnosed with cancer - year
Question Text: In what year were you diagnosed with this cancer?
Question Header: Please enter your response and then touch "NEXT".
Question Type: Open Ended, Numeric
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

014 - First diagnosed with cancer - month
Question Text: In what month of <First diagnosed with cancer - year> were you diagnosed
with this cancer?
Question Header: Please touch your response. If you are unsure, please make your best guess. Then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

015 - Second diagnosis
Question Text: Have you ever had a second diagnosis or recurrence?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Multiple Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence
016 - Treatment stage
Question Text: Please select the option which best describes where you are up to with your treatment.
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

017 - Treatment aim
Question Text: What do you understand to be the main aim of your current cancer treatment?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question "016 - Treatment stage" Button: “03 - Receiving treatment (e.g. chemotherapy, radiation therapy)” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

018 - Type of health insurance
Question Text: What type of private health insurance do you have?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

019 - Country of birth
Question Text: Were you born in Australia?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The following choices cause the survey to continue with other than the next question in sequence:
Button: “01 – Yes” causes the survey to continue with Question: “022 ATSI status”

020 - Other 019
Question Text: What is your country of birth?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “019 - Country of birth” Button: “02 – No” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

021 - Other country
Question Text: Please specify your country of birth.
Question Header: Please insert your answer using the keyboard on screen.
Question Type: Open Ended, Verbatim Text
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “020 - Other 019” Button: “14 – Other” is selected
Branch Condition: The survey will continue with the next question in sequence

022 - ATSI status
Question Text: Are you of Aboriginal or Torres Strait Islander background?
Question Header: Please select all that apply, and then touch "NEXT".
Question Type: Closed Ended, Multiple Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “019 - Country of birth” Button: “01 – Yes” is selected
Branch Condition: The survey will continue with the next question in sequence

023 - Living
Question Text: Who lives with you?
Question Header: Please select all that apply, and then touch "NEXT".
024 - Outpatient appointments at this clinic
Question Text: On how many separate occasions IN THE LAST 3 MONTHS have you attended an outpatient appointment AT THIS CLINIC?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

025 - Outpatient appointments at this clinic - other
Question Text: Please specify how many outpatient appointments you have attended AT THIS CLINIC IN THE LAST 3 MONTHS.
Question Header: Please enter your response and then touch "NEXT".
Question Type: Open Ended, Numeric
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “024 - Outpatient appointments at this clinic” Button: “12 - More than 10” is selected
Branch Condition: The survey will continue with the next question in sequence

026 - Number of times seen cancer doctor
Question Text: On how many separate occasions IN THE LAST 3 MONTHS have you had an appointment with your cancer doctor(s) at this hospital?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence
027 - Number of times seen cancer doctor - calculator
Question Text: Please specify how many appointments you have had with your cancer doctor(s) at this hospital IN THE LAST 3 MONTHS.
Question Header: Please enter your response and then touch "NEXT".
Question Type: Open Ended, Numeric
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question "026 - Number of times seen cancer doctor" Button: "12 - More than 10" is selected
Branch Condition: The survey will continue with the next question in sequence

028 - Quality of care info screen
Question Text: Quality of Cancer Care
Question Header: Please read the text below and then touch "NEXT" to continue
Question Type: Information Screen
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

029 - Quality of care - physical symptoms
Question Text: During my cancer care, my well-being would have been greatly improved by:
   BETTER MANAGEMENT OF MY PHYSICAL SYMPTOMS.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

030 - Quality of care - Information and communication
Question Text: During my cancer care, my well-being would have been greatly improved by:
   BETTER INFORMATION AND COMMUNICATION ABOUT MY CANCER AND CARE.
Question Header: Please touch your level of agreement with this and then touch
"NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

031 - Quality of care - emotional and spiritual support
Question Text: During my cancer care, my well-being would have been greatly improved by:
BETTER EMOTIONAL AND/OR SPIRITUAL SUPPORT.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

032 - Quality of care - services, information and support for family
Question Text: During my cancer care, my well-being would have been greatly improved by:
BETTER SERVICES, INFORMATION AND SUPPORT FOR MY FRIENDS/FAMILY.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

033 - Quality of care - staff approachability and respect for me
Question Text: During my cancer care, my well-being would have been greatly improved by:
BETTER STAFF APPROACHABILITY AND RESPECT FOR ME.
Question Header: Please touch your level of agreement with this and then touch
"NEXT".

Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

034 - Quality of care - getting access to the care I need when required
Question Text: During my cancer care, my well-being would have been greatly improved by:
GETTING BETTER ACCESS TO THE CARE I NEED WHEN REQUIRED.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

035 - Quality of care - services and support to cope with changes to my relationships
Question Text: During my cancer care, my well-being would have been greatly improved by:
BETTER SERVICES/SUPPORT TO COPE WITH CHANGES TO MY RELATIONSHIPS.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

036 - Quality of care - services or advice to assist with practical concerns
Question Text: During my cancer care, my wellbeing would have been greatly improved by:
BETTER SERVICES/ADVICE TO ASSIST ME WITH PRACTICAL CONCERNS.
Question Header: Please touch your level of agreement with this and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

037 - Quality of care - improvement ranking
Question Text: Please rank up to 3 aspects of cancer care that would have helped you the most if they were improved:
Question Header: In order, touch the 1st, 2nd and then 3rd most important areas for improvement.
Question Type: Closed Ended, Multiple Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

038 - Willingness to complete section
Question Text: The following questions ask for your views about your life expectancy. This will provide information that may help to improve services for cancer patients.
Question Header: Please indicate whether or not you are willing to complete these questions by touching your response.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

039 - Life expectancy discussion preferences
Question Text: When discussing life expectancy, I would prefer my doctor to:
Question Header: Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".
Question Type: Opinion Grid
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “038 - Willingness to complete section” Button: “01 - I am willing to complete this section of the survey” is selected
Branch Condition: The survey will continue with the next question in sequence

040 - Life expectancy discussion
Question Text: Have you and your cancer doctor talked about your life expectancy?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “038 - Willingness to complete section” Button: “01 - I am willing to complete this section of the survey” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

041 - Life expectancy discussion initiation
Question Text: How did the discussion about life expectancy begin?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “040 - Life expectancy discussion” Button: “01 – Yes” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

042 - Life expectancy - which cancer doctor
Question Text: Which doctor/s have you discussed your life expectancy with?
Question Header: Please touch all responses that apply to you and then touch "NEXT".
Question Type: Closed Ended, Multiple Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “040 - Life expectancy discussion” Button: “01 – Yes” is selected
Branch Condition: The survey will continue with the next question in sequence
043 - Life expectancy estimate
Question Text: While my cancer doctor cannot be certain, he/she has told me that it is probable that:
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “040 - Life expectancy discussion” Button: “01 – Yes” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

044 - Life expectancy - agreement with estimates
Question Text: Do you agree with the life expectancy estimate that your cancer doctor gave you?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “043 - Life expectancy estimate” as a whole question is answered
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

045 - Life expectancy discussion outcomes
Question Text: The information my cancer doctor gave me on life expectancy:
Question Header: Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".
Question Type: Opinion Grid
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “043 - Life expectancy estimate” as a whole question is answered
Branch Condition: The survey will continue with the next question in sequence
046 - Life expectancy - do you want to discuss
Question Text: Would you like to talk to your cancer doctor about your life expectancy?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “040 - Life expectancy discussion” Button: “02 – No” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

047 - Life expectancy - why not discussed yet
Question Text: Why haven't you discussed life expectancy with your cancer doctor?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “046 - Life expectancy - do you want to discuss” Button: “01 – Yes” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

048 - Life expectancy - any health professionals
Question Text: Have you talked to any other health professionals about how cancer might influence your life expectancy?
Question Header: Please touch all responses that apply to you and then touch "NEXT".
Question Type: Closed Ended, Multiple Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
   If Question “040 - Life expectancy discussion” as a whole question is answered
Branch Condition: The survey will continue with the next question in sequence

049 - Life expectancy - hindsight preferences
Question Text: Given what you know now, how do you feel about
being given life expectancy information?

**Question Header:** Please touch your response and then touch "NEXT".

**Question Type:** Closed Ended, Single Choice

This question does NOT belong to a Randomizer Group and is NOT hidden.

**Skip Conditions:** This question will not be skipped if the following conditions are met:
- If Question "040 - Life expectancy discussion" Button: "01 - Yes" is selected

**Branch Condition:** All answer choices cause the survey to continue with the next question in sequence

**050 - HADS Info**

**Question Text:** Hospital Anxiety and Depression Scale (HADS)

**Question Header:** Please read the text below and then touch "NEXT" to continue.

**Question Type:** Information Screen

This question does NOT belong to a Randomizer Group and is NOT hidden.

**Skip Conditions:** This question is not subject to any skip condition

**Branch Condition:** The survey will continue with the next question in sequence

**051 - HADS1**

**Question Text:** I feel tense or “wound up”.

**Question Header:** Please select the option that most closely describes how you have been feeling in the past week.

**Question Type:** Closed Ended, Single Choice

This question does NOT belong to a Randomizer Group and is NOT hidden.

**Skip Conditions:** This question is not subject to any skip condition

**Branch Condition:** All answer choices cause the survey to continue with the next question in sequence

**052 - HADS2**

**Question Text:** I still enjoy the things I used to enjoy.

**Question Header:** Please select the option that most closely describes how you have been feeling in the past week.

**Question Type:** Closed Ended, Single Choice

This question does NOT belong to a Randomizer Group and is NOT hidden.

**Skip Conditions:** This question is not subject to any skip condition

**Branch Condition:** All answer choices cause the survey to continue with the next
053 - HADS3
Question Text: I get a sort of frightened feeling as if something awful is about to happen.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

054 - HADS4
Question Text: I can laugh and see the funny side of things
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

055 - HADS5
Question Text: Worrying thoughts go through my mind.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

056 - HADS6
Question Text: I feel cheerful.
Question Header: Please select the option that most closely describes how you have
been feeling in the past week.

Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

057 - HADS7
Question Text: I can sit at ease and feel relaxed.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

058 - HADS8
Question Text: I feel as if I am slowed down.
Question Header: Please touch your response.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

059 - HADS9
Question Text: I get a sort of frightened feeling like "butterflies" in the stomach.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence
060 - HADS10
Question Text: I have lost interest in my appearance.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

061 - HADS11
Question Text: I feel restless as if I have to be on the move.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

062 - HADS12
Question Text: I look forward with enjoyment to things.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

063 - HADS13
Question Text: I get sudden feelings of panic.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
064 - HADS14
Question Text: I can enjoy a good book or radio or TV programme.
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

065 - A and D - Treatment preferences
Question Text: IF YOU WERE experiencing ANXIETY OR DEPRESSION, would you accept the following types of professional help?
Question Header: Please touch the answer that best describes your level of agreement with each item and then touch "NEXT".
Question Type: Opinion Grid
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: The survey will continue with the next question in sequence

066 - ANXIETY - Self rated anxiety
Question Text: What level of ANXIETY have you been experiencing IN THE LAST WEEK?
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence
067 - DEPRESSION – Self-rated depression
Question Text: What level of DEPRESSION have you been experiencing IN THE LAST WEEK?
Question Header: Please select the option that most closely describes how you have been feeling in the past week.
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

068 - A and D - Current levels and support preferences
Question Text: Given your current levels of ANXIETY AND/OR DEPRESSION, would you like to be offered some professional help?
Question Header: Please touch your response and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question is not subject to any skip condition
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

069 - A and D - why don’t you want support
Question Text: Why don’t you want professional support for ANXIETY and/or DEPRESSION?
Question Header: Please touch all responses that apply to you and then touch "NEXT".
Question Type: Closed Ended, Single Choice
This question does NOT belong to a Randomizer Group and is NOT hidden.
Skip Conditions: This question will not be skipped if the following conditions are met:
If Question “068 - A and D - Current levels and support preferences” Button: “02 – No” is selected
Branch Condition: All answer choices cause the survey to continue with the next question in sequence

070 - Thank you(1)
Question Text:
Question Type: Information Screen
This question does NOT belong to a Randomizer Group and is NOT hidden.

Skip Conditions: This question is not subject to any skip condition

Branch Condition: The survey will continue with the next question in sequence